

RACIAL DISPARITIES IN HEALTH CARE: CONFRONTING UNEQUAL TREATMENT

HEARING

BEFORE THE
SUBCOMMITTEE ON CRIMINAL JUSTICE,
DRUG POLICY AND HUMAN RESOURCES
OF THE

COMMITTEE ON
GOVERNMENT REFORM

HOUSE OF REPRESENTATIVES

ONE HUNDRED SEVENTH CONGRESS

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RACIAL DISPARITIES IN HEALTH CARE: CONFRONTING UNEQUAL TREATMENT

TUESDAY, MAY 21, 2002

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON CRIMINAL JUSTICE, DRUG POLICY AND
HUMAN RESOURCES,
COMMITTEE ON GOVERNMENT REFORM,
Washington, DC.

The subcommittee met, pursuant to notice, at 12:09 p.m., in room 2154, Rayburn House Office Building, Hon. Mark E. Souder (chairman of the subcommittee) presiding.

Present: Representatives Souder, Cummings, and Davis of Illinois.

Also present: Representative Waxman.

Staff present: Christopher Donesa, staff director and chief counsel; Roland Foster, professional staff member; Conn Carroll, clerk; Julian A. Haywood, minority counsel; Karen Lightfoot, minority senior policy advisor; Josh Sharfstein, minority professional staff member; and Jean Gosa, minority assistant clerk.

Mr. SOUDER. The subcommittee will now come to order.

Good afternoon. I'd like to thank all of you for being here today. I want to start by recognizing and thanking Ranking Member Cummings for raising the issue of racial disparities in health care. We have scheduled today's hearing at his request.

I would like to express my own serious concerns at the findings which we will be reviewing today. They ought to be of concern to all Americans because the Institute of Medicine has raised fundamental questions that could continue to weaken public perception of the health care system, threaten to perpetuate a health gap between minorities and nonminorities if not addressed, and further challenge already beleaguered health care providers.

A comprehensive report by the Institute of Medicine released in March of this year found that minorities in America generally receive poorer health care than whites even when income, insurance and medical conditions are similar. The IOM found that this inequality has contributed to higher minority death rates from a host of chronic conditions.

For example, relative to Caucasians, African Americans and Hispanics are less likely to receive appropriate cardiac medication or to undergo coronary artery bypass surgery even when factors such as insurance and income are taken into account. African Americans with end-stage renal disease are less likely to receive hemodialysis and kidney transplantation, and African American and Hispanic

patients with bone fractures seen in hospital emergency departments are less likely than whites to receive pain medication.

The report identified a number of causes for racial health disparities including language barriers, inadequate coverage, provider bias and lack of minority doctors.

In addition to other recommendations for remedying these disparities which we will discuss more in depth, the IOM suggested that public awareness should be raised of this issue. We hope to further that goal today and discuss with representatives from the administration and other witnesses how best to close the gap.

The IOM report is at least the fourth study released this year indicating racial disparities in the health care system. A January Centers for Disease Control and Prevention [CDC], report found that although the health gap between whites and minorities narrowed in the 1990's, substantial disparities remain. A Commonwealth Fund survey released earlier this month found that minorities do not fare as well as whites on almost every measure of health care quality. And a Harvard study released earlier this month found that African American patients enrolled in Medicare/Choice plans receive poorer quality of care than Caucasian patients across several measures.

In November 2000, Congress passed the Minority Health and Health Disparities Research and Education Act of 2000, which is now Public Law 106-525, to confront many of the shortcomings noted in these reports. This law established the National Center on Minority Health and Health Disparities at the National Institutes of Health, provided increased fundings and incentives for minority health and health disparities research and new support for education for both health professionals and patients to increase positive health outcomes for minorities. It also provided funding for schools that are researching health disparities.

While it is too soon to determine what effects this law has made, it is clear that more must be done to improve patient care for minorities. Particularly patients must have the ability to take control of their own health care decisionmaking. To do so will require improved patient education access to affordable care and more choice in making health care decisions.

I look forward to today's testimony from the administration and health care leaders on how best to move toward meaningful progress, and I want to encourage the Department of Health and Human Services to move promptly toward tangible steps to help level the quality of care.

Again, I thank Congressman Cummings for his leadership in bringing this important issue before us today, and I look forward to continuing to work in the subcommittee toward an equality of health care opportunities and care for all Americans.

[The prepared statement of Hon. Mark E. Souder follows:]

Opening Statement
Chairman Mark Souder

“Racial Disparities in Healthcare:
Confronting Unequal Treatment”

Subcommittee on Criminal Justice, Drug Policy,
and Human Resources
Committee on Government Reform

May 21, 2002

Good afternoon and thank you all for being here today.

I want to start by recognizing and thanking Ranking Member Cummings for raising the issue of racial disparities in health care. We have scheduled today’s hearing at his request, and I would like to express my own serious concern at the findings which we will be reviewing today. They ought to be of concern to all Americans, because the Institute of Medicine has raised fundamental questions that could continue to weaken public perception of the health care system, threaten to perpetuate a “health gap” between minorities and non-minorities if not addressed, and further challenge already beleaguered health care providers.

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and African American and Hispanic patients with bone fractures seen in hospital emergency departments are less likely than whites to receive pain medication.

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Again, I thank Congressman Cummings for his leadership in bringing this important issue before us today and I look forward to continuing to work in the Subcommittee toward equality of health care opportunity and care for all Americans.

Mr. SOUDER. I'd now like to yield to Mr. Cummings for an opening statement.

Mr. CUMMINGS. Thank you, Mr. Chairman, and I thank you for agreeing to my request to holding this important hearing today. Today we will examine the progress that this Nation is making toward creating a health care system in which being a minority is not a mortality factor. As a Member of Congress and as an American of color, I deeply appreciate your willingness to examine the unequal treatment that minority Americans continue to receive within America's health care system, especially the compelling and disturbing evidence analyzed by a blue ribbon panel of scientists under the auspices of the Institute of Medicine.

I join with you, Mr. Chairman, in welcoming all of our witnesses from the Department of Health and Human Services today, and particularly I want to thank Dr. Ruffin for being here under very difficult circumstances. Your presence here today speaks volumes about your commitment to fighting the persistent disparities we find in our Nation's health care system, and I thank you.

And our second panel, we'll hear from our colleague Congressman Donna M. Christensen from the Virgin Islands, a physician who has a long-standing interest in issues surrounding minority health disparities; as well as Dr. Elena Rios, president of the National Hispanic Medical Association.

Finally, let me also express a special welcome to the important witnesses who are joining us here today from Johns Hopkins University in Maryland's 7th Congressional District, which is, of course, the district I represent. Dr. Thomas LaVeist, the associate professor in the Bloomberg School of Public Health, and Dr. Lisa A. Cooper, who serves as associate professor on the faculties of both the Bloomberg School of Public Health and the School of Medicine.

Mr. Chairman, in 1998, with strong encouragement from the Congressional Black Caucus, President Clinton committed this Nation to eliminating racially based health disparities in six specific areas by the year 2010. Those areas were infant mortality, cancer, cardiovascular diseases, diabetes, HIV infection, AIDS and immunizations. To their credit HHS Secretary Thompson and the Bush administration have reaffirmed this important national objective.

Naturally, in order to cure and eliminate minority health disparities, we must first arrive at the understanding of their nature and causes. That is why I was proud to join with Congressman Bennie Thompson of Mississippi and other colleagues who care deeply about this issue in sponsoring legislation to create the National Center on Minority Health and Health Disparities at the National Institutes of Health. The Center's support for the IOM disparity studies was critical, and I want to recognize the efforts of my good friend and colleague Congressman Jesse Jackson, Jr., and the other Members of Congress who worked diligently to secure funding for the Center and for the study in the appropriations process.

Today we will discuss the implications of that study entitled *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. The IOM's central conclusion is that Americans of color tend to receive lower quality health care even when the patient's income and insurance plans are the same, and that these disparities contribute to our higher death rates and poorer health

outcomes from heart disease, cancer, diabetes, HIV/AIDS and other life-endangering conditions.

This unfortunate indictment of our health care system by America's health care establishment is a monumental moral challenge to the policymakers of this great country. We have known for years that Americans of color die before our time from a wide range of illnesses, and that black mortality rates are higher than those of Caucasians. While lack of health care access has played an obvious role, the impact of racial biases and stereotypes on the quality of medical care received has been more difficult to assess. The IOM report demonstrates that these phenomena do exist, and we must now ensure that America's medical establishment comes to terms with the impact of race as an independent factor.

When we know that the quality of care one receives in a doctor's office or in an emergency room may depend upon the color of one's skin, it is clear that we are dealing with a national civil rights issue of the highest order, and we must address it in those terms. Unless we dramatically expand the civil rights remedies available to people of color, the national 2010 initiative to eliminate racial and ethnic health disparities will simply fail. Title 6 enforcement is critical, and we must provide resources to the Office of Civil Rights so that it can aggressively enforce the civil rights laws and regulations that exist to protect Americans from discrimination in the health care system. Discriminatory effects of policies that limit minority access to medical care continue to be deadly, and without effective remedies, we will not see them go away.

Our witnesses will address a range of other initiatives that must be undertaken if we were to achieve the administration's goal, the Nation's goal, of ending racial disparities in health care. As the IOM report tells us, education of both patients and providers improved data collection and monitoring, and increasing the proportion of minority health professionals are prominent among them.

Mr. Chairman, I hope we can develop some consensus around implementing these initiatives so that the race will no longer be a predictor of negative health care outcomes, and I again thank you for holding this hearing. Thank you as well to all of our witnesses for being with us today. I look forward to hearing your testimony.

Mr. SOUDER. Thank you.

I now yield to Mr. Davis.

Mr. DAVIS OF ILLINOIS. Thank you, Mr. Chairman, and let me first of all thank you for holding this hearing. I also want to commend the ranking member, Representative Cummings, for bringing this subject matter to this venue.

I would like to ask for permission to submit my statement for the record, to revise and extend it, and also thank my young colleague who's graduating from medical school next month, Scott, for preparing it. And I look forward to attending his graduation, where I am scheduled to be the commencement speaker.

I've been around this issue now for close to 40 years, and we've been talking about disparities. When it comes to minorities, there are disparities in everything that deal with quality of life in these United States of America. And I guess if there's anything that I've learned, one of the things that I've learned and discovered is that change is oftentimes a rather slow and subtle process. Matter of

fact, people have been talking about problems of health care in a documented way in this country ever since the 1800's, when I guess one of the first real studies were put together in Massachusetts, something called the Shattuck report. And I find that the same problems that were being talked about then are being talked about now relative to what the issues are when it comes to health care.

Obviously one of the real factors contributing to disparities facing African Americans and other minority groups is the disparity of income, is the issue of poverty, the issue of people being poor and not having resources.

I always suggest that my mother died prematurely because she had to travel from the small town where she lived in Arkansas to the University Medical Center in Little Rock in order to get treatment for the dialysis problem, the kidney problems that she was having.

I've known other individuals who could not get treatment because there was not the availability of resources where they were. And then, of course, you look in other places and there is an overabundance of resources.

I represent a congressional district that has 23 hospitals in it, four medical schools, 25 community health centers, three or four large research institutes. And so the problem there is not necessarily the unavailability of care. But you can go 2 miles from the largest medical center complex in the country, which is in my congressional district, and find some of the most dire health needs and health statistics that exist.

And so it seems to me that in many ways we have a certain amount of skill; we probably do some of the best medical education in the world. Something called the Flexner Report was put out, but—not only did it improve medical education, but it also put most of the black medical schools out of business, and they have not come back yet. I think it left only two, Howard and Meharry.

So it seems to me that when we talk about disparities, we're really talking about how willing are we, as a Nation, to live up to the notion that we can move toward equal justice, equal opportunity. There is still a paucity of African Americans who are trained medical personnel. You look at the disparities in terms of the numbers of physicians and other professionals who are African Americans, and we still have the same problem. And so there needs to be a revamping, I think, of the system, more emphasis placed upon education, more emphasis placed upon life-style, more emphasis placed upon the desire and the need to be healthy.

Of course, when it comes to racism and race orientation and all of those factors, we know that's not so much a factor of skill, but it's a factor of will.

And so the struggle must continue. One of the things that Frederick Douglass taught that I try and subscribe to is that if there is no struggle, there is no progress. And so when you, Mr. Chairman, will hold a hearing on this subject in this committee, that is a part of the continuing and ongoing struggle.

And you, Mr. Cummings, when you will raise the issue in this committee so that we can have the kind of discussion with the experts who have come to testify—and I want to thank all of them for coming and bringing their expertise. But what we really need

to do is move toward a national health system, a national health plan, everybody in, nobody out, a system that takes the idea that health care is indeed a right and not a privilege. And a country with as much technology, with as much proficiency, as much resource and as much understanding as we have can, in fact, do that.

So I thank you and look forward to the information that will be shared by our expert panelists. And I yield back the balance of my time.

[The prepared statement of Hon. Danny K. Davis follows:]

Danny K. Davis
5-21-02

"Racial Disparities in Healthcare: Confronting Unequal Treatment"
Statement of Danny K. Davis

Mr. Chairman, I thank you
for covering this matter today
discussing "Racial Disparities
in Healthcare: Confronting
Unequal Treatment". In a
time where healthcare and
healthcare workers are

fighting for fair funding from the Centers of Medicaid and Medicare Services (CMS), minority patients have been fighting for fair treatment from healthcare workers for years. Many studies have documented the poor health

and health outcome of
minorities, reflecting a long
history of economic
deprivation and barriers to
healthcare.

One of the studies named ^{by}
"The Commonwealth Fund

2001 Health Care Quality

Survey" highlighted

continuing areas of concern.

On the issue of Health

Insurance and Access to

Care, about one-third of

African Americans ages 18 to

64 were uninsured during the

year (30%), compared with one of five (20%) non-elderly white adults. Also, African-Americans non-elderly adults are less likely to have job-based insurance (59% black vs. 70% white) and more

likely to use public programs
(11% black vs. 4%white).

Hispanics have been
documented with the highest
uninsured rate among all
racial or ethnic groups. About
half of Hispanics under age
65 (46%) report no insurance

during the past year as
compared to whites (20%).

One of five Asian American
adults ages 18 to 64 is
uninsured in the past year
with especially high rates for
Korean and Vietnamese
Americans.

On the issue of health status
and health habits, African-
Americans were generally at
or above national averages
for diagnoses of high blood
pressure, heart disease,
cancer, diabetes, obesity, and

asthma. Overall, Hispanics
are less likely to report a
chronic disease than the total
U.S. population.

On the issue of Patient-
Physician Interaction, 23
percent of African-Americans

compared with 16 percent of whites report one or more measures of poor communication with their physician. In the Hispanic population, 33 percent of Hispanics report they had a problem understanding or

communicating with their
doctor. Asian Americans
were less likely to rate their
care highly, less likely to be
confident about their care,
and more likely to indicate
having a communication
problem with their physician.

These statistics are alarming
to hear but it is reality. These
are a few of the major
reasons minorities morbidity
rates are increasing
astronomically. In a time of
limited resources for

physicians and health care
workers, the health gap
between minorities and non-
minorities is increasing. As a
nation, we need to increase
public awareness, implement
evidence-based guidelines for
medical treatment, improve

Mr. Chairman I would like to
see a miracle happen today
and let us end racial
disparities in healthcare in
this country.

Mr. SOUDER. I'd like to yield to the distinguished gentleman from California, the ranking member of the full committee and member of the subcommittee, Mr. Waxman.

Mr. WAXMAN. Thank you, Mr. Chairman.

Democrat or Republican, conservative or liberal, I do not believe there is any Member of Congress who can ignore the findings of the March 2002 report from the Institute of Medicine called "Unequal Treatment." This landmark report surveyed hundreds of scientific studies and found significant disparities in medical treatment and life-or-death outcomes by race and ethnicity.

What the report found was tragic. Minorities are less likely to receive needed cardiac medication and cardiac surgery and are less likely to receive kidney dialysis or transplants. Minorities are also less likely to receive the most effective treatments for HIV. Minorities are also less likely to have their pain adequately treated. The list goes on and on.

Here in Congress we are proud of our record of expanding NIH funding to develop new breakthrough treatments for diseases that cause immense human suffering, but these efforts are tarnished if we cannot make the treatments available. We have accomplished little if we permit the fruits of research to remain out of the reach of so many thousands of American citizens.

It is a testament to the importance of this issue that the Subcommittee on Criminal Justice has called this hearing in bipartisan fashion, and I commend the Chair, Representative Souder, and the ranking member, Representative Cummings, for their leadership.

Today, we will hear about the findings of the Institute of Medicine panel. We will also discuss solutions. It is not enough just to denounce health disparities. We must also take action to reduce them. The Institute of Medicine report includes a set of recommendations that I hope we will explore today.

For example, one recommendation is that patients with public insurance receive the same managed care protections as those in private insurance. Because patients on Medicaid and other public insurance programs are disproportionately minorities, inadequate patient protections can increase health disparities. We need to ask whether the current administration is committed to following this recommendation.

The Institute of Medicine panel also supports funding for innovative efforts to deliver medical care so that all patients, regardless of ethnicity or race, receive necessary treatments. We need to ask whether the current administration has supported full funding for such initiatives.

The Agency for Healthcare Research and Quality has developed a program to accomplish some of these ideas. We need to ask whether the current administration is supporting full funding for these initiatives.

The report calls for efforts to fight discrimination against racial and ethnic minorities in the health care system. We need to ask whether the current administration has backed away from a rule to prevent discrimination against Medicaid patients, many of whom are minorities.

I am pleased that the administration has sent several witnesses from the Department of Health and Human Services here today. I

am also pleased that several experts from medical professional associations and the Institute of Medicine have come for today's second panel. And I hope that today's hearing is not an end, but a beginning. By discussing the policies that are necessary to address health disparities, this hearing can be an important step toward a greater understanding of the commitment that Congress, as well as the medical profession, must make to provide equal treatment in the United States.

Thank you very much, Mr. Chairman.

Mr. SOUDER. Thank you.

[The prepared statement of Hon. Henry A. Waxman follows:]

**Statement of the Honorable Henry A. Waxman
Ranking Minority Member
Committee On Government Reform**

**Hearing on Hearing on Racial Disparities in Healthcare
before the Subcommittee on Criminal Justice, Drug Policy and Human Resources**

May 21, 2002

Chairman Souder,

Democrat or Republican, conservative or liberal, I do not believe there is any Member of Congress who can ignore the findings of the March 2002 report from the Institute of Medicine called Unequal Treatment. This landmark report surveyed hundreds of scientific studies and found significant disparities in medical treatment and life-or-death outcomes by race and ethnicity.

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Thank you very much.

Mr. SOUDER. Before proceeding, I'd like to take care of a couple of procedural matters.

First, I ask unanimous consent that all Members have 5 legislative days to submit written statements and questions for the hearing record, that any answers to written questions provided by the witnesses also be included in the record.

Without objection, it is so ordered.

Second, I ask unanimous consent that all exhibits, documents and other materials referred to by Members and the witnesses may be included in the hearing record and that all Members be permitted to revise and extend their remarks.

Without objection, it is so ordered.

We begin with our panel of administration witnesses. We have excellent representation from the department today, for which I'd like to thank each of you and the department. As I'm sure most of you know, we also ask you to summarize your testimony in 5 minutes, and we will include your complete statement in the record. As an oversight committee, it's our standard practice to ask all of our witnesses to testify under oath, so if each of you could rise, I'll administer the oath.

[Witnesses sworn.]

Mr. SOUDER. Let the record show that each witness responded in the affirmative.

As you have heard, Dr. John Ruffin, Director of the National Center on Minority Health and Health Disparities, has had some family matters that he has to attend to. And we want to express our sympathy to you and your family for your struggles. And because of that, we're going to have you give your testimony and then take some questions; and then you can be excused because we know you need to get on to that.

But we thank you for taking the time to come to us today for this hearing.

STATEMENTS OF JOHN RUFFIN, Ph.D., DIRECTOR, NATIONAL CENTER ON MINORITY HEALTH DISPARITIES, NATIONAL INSTITUTES OF HEALTH; NATHAN STINSON, JR., Ph.D., M.D., M.P.H., DEPUTY ASSISTANT SECRETARY FOR MINORITY HEALTH, OFFICE OF PUBLIC HEALTH AND SCIENCE; RUBEN KING-SHAW, JR., DEPUTY ADMINISTRATOR AND CHIEF OPERATING OFFICER, CENTERS FOR MEDICARE AND MEDICAID SERVICES; CAROLYN CLANCY, M.D., ACTING DIRECTOR, AGENCY FOR HEALTHCARE RESEARCH AND QUALITY, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Mr. RUFFIN. Thank you, Mr. Chairman.

Good afternoon, Mr. Chairman and Mr. Cummings and other members of the subcommittee. I'm honored to join you today as the first Director of the National Center on Minority Health and Health Disparities for this special hearing on racial disparities in health.

It is quite timely for me to update you on work of the new center to eliminate health disparities in light of the recent findings in the IOM report.

To echo the words of the Deputy Secretary of Health and Human Services Claude Allen, these are issues that we in the Department

have been confronting and working to resolve for many years. We are always alarmed, however, by the extent and impact of health disparities across our Nation.

One of the great challenges we have faced over the past decade is the need to convince people that these problems are real and that they can be addressed through science. The IOM report helped greatly in this regard by serving to further document this crisis.

As you know, the new center at the NIH was created by Public Law 106-525, the Minority Health and Health Disparities Research and Education Act of 2000. The timing could not have been better. The law has helped us transition from the NIH Office of Research on Minority Health to a new center designated to address health disparity issues from a research perspective. The Center cannot do this alone, however. In fact, no single agency can do this alone. The health disparity crisis is multifaceted and will require a multidisciplinary approach from institutions across the country.

Ours is an NIH-wide effort with the Center at the focal point. To reduce and eliminate health disparities, we will work with our other partners at NIH, but we will also work with other agencies and outside organizations and institutions involved in health disparities.

We at the table this morning are networking among ourselves and with our constituencies. Only in this way will we be able to produce the results that will address the IOM recommendations. We have asked our stakeholders across the country what should we be doing that we're not doing. We have taken their advice and are now developing the NIH strategic plan and budget to reduce and, ultimately, eliminate health disparities.

We also have three core programs provided in law that established our center. Our loan repayment program will give us an opportunity to produce a core of individuals who are culturally sensitive to health disparities. This type of program has worked well in other areas, such as HIV/AIDS. This work force—doctors, researchers, nurses, health care professionals—will sensitize even more individuals to the health disparities and help us combat the crisis.

In fiscal year 2001, as a result of the creation of the Center and the creation of the loan repayment program, 8 months after the creation of the Center, 45 health professionals received loan repayment programs or loan repayment awards. We will set up a new round of competition for additional awards to be made this year.

We must sensitize not only individuals, but also institutions to the health disparity crisis. Our endowment program, also provided by law, is available to section 736 institutions under the Public Service Act. This program will provide assistance for training and research and will bring more individuals into the health disparity research arena. Seven institutions were approved for awards in fiscal year 2001. Payments already have been made to five of these institutions, and payments are on the way for the other two institutions.

We also are now accepting applications for the next round of competition and plan to make more awards this year. This is a collaborative effort between the National Institutes of Health and HRSA.

The crown jewel of all of our efforts will be the creation of our Health Disparity Centers of Excellence around the country. We will establish these centers across the country to level the playing field supporting a wide array of institutions to engage in research, research training and health disparities.

We have developed three mechanisms, Mr. Chairman, of support for this program in order to involve institutions at all levels of capability. We are currently accepting applications and plan to make awards this year.

We also continue to build upon our collaborative relationships with our HHS partners, many of whom are sitting at the table. Last year, we participated in 214 collaborative projects. This year we have received over 250 requests to cofund new initiatives from other NIH institutes and centers. This is a testament—it is an indication of the seriousness of the health disparity issues.

While we would like to fund them all, there are congressional mandates within the new center that we're also committed to. However, we will maintain our obligation to several other NIH institutes and centers projects as well as our support to various OMH, AHRQ and CDC projects.

With the Centers for Disease Control, we continue to support the Reach 2010 program of Racial and Ethnic Approaches to Community Health, which is entering its second phase. This program is a cornerstone initiative aimed at eliminating disparities in health status experienced by ethnic minority populations, and I'm sure those at CDC will talk more about their collaboration with the National Institutes of Health and our support for that program.

The collaboration of the National Center on Minority Health and Health Disparities collaborated with the Office of Minority Health of the Department of Health and Human Services. It is broad-based, and it includes the goals of increasing research on minority health issues, collecting data, improving the data base, increasing the recruitment and retention of minority students in biomedical science and conducting community outreach and public education programs.

There's a whole host of programs for which we collaborate with the Office of Minority Health with AHRQ. The Agency for Healthcare Research and Quality supports several programs aimed at understanding and eliminating health disparities that focus on community outreach, building research capacity and training. The Center provides funding for many of these projects, particularly the EXCEED program. It is our intent to continue to support these efforts and to continue to collaborate with our various partners.

The Center continues to explore and develop future initiatives for research activities and programs aimed at reducing and eliminating health disparities. We will be meeting with our new advisory council in the coming weeks to discuss a number of new initiatives that we plan to launch.

The Center is considering a cultural competency initiative which addresses the need for the development of cultural competency among health care providers and others who participate in health care processes. There is an urgent need, Mr. Chairman, for such individuals to have a firm grasp on how various belief systems, cultural bias, family structures, historical realities and a host of other

culturally determined factors influence the way people experience illnesses and the way they respond to advice and treatment. We understand that such differences are real and translate into real differences in the outcome of care.

We will explore with our advisory council the establishment of health disparity community centers that will conduct research, provide shared resources and provide the formal infrastructure to facilitate rapid advances in knowledge about communication among health disparity populations. These interdisciplinary efforts will result in new theories, methods and intervention that will contribute to addressing and ultimately eliminating disparities in health status.

Finally, Mr. Chairman, the Center is grateful to the Congress, the administration, the NIH institutes and centers and to all of you for the overwhelming support that you have provided the Center in transitioning from the Office of Research on Minority Health to the National Center on Minority Health and Health Disparities. I'm proud of the progress that the Center has made over the past year in establishing its organizational structure and programs. We will continue to work with our many partners to explore new opportunities to reduce and eliminate health disparities.

Through continued and increasing collaborative ventures, the Center will work diligently to define the health disparity issue for every American and garner support to ensure the health of all Americans.

Health disparity is an issue that transcends minorities and other health disparity populations. Clearly, it is everybody's concern and it calls for shared responsibilities to effect permanent change. Each year we will be providing an annual report to the Congress on the result of our activities. We would be pleased, Mr. Chairman, to keep your subcommittee informed of our progress as well.

Thank you for the opportunity to speak with you today.

[The prepared statement of Mr. Ruffin follows:]



Testimony
Before the Subcommittee on Criminal Justice,
Drug Policy, and Human Resources
Committee on Government Reform
United States House of Representatives

**NIH's Role in Eliminating Health
Disparities**

Statement of

John Ruffin, Ph.D.

Director,

National Center on Minority Health Disparities,

National Institutes of Health,

U.S. Department of Health and Human Services

For Release on Delivery
Expected at Noon
on Tuesday, May 21, 2002

Good Afternoon:

I am honored to join you today as the first Director of the National Center on Minority Health and Health Disparities (NCMHD) for this special hearing on Minority Health Disparities. I am thankful to the Congress for realizing the need, listening to the American people, and helping to enact legislation to create the Center. This is a great opportunity for me to update you on the activities of the NCMHD in light of the recent findings in the Institute of Medicine's report -- "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care."

As creators of the law, health disparities advocates and health professionals, I need not tell you the statistics and the disproportionate burden of disease and death from cancer, stroke, heart disease and diabetes that confront minority populations. You also recognize that while the United States has made great strides in advancing the health of the nation, not everyone has benefitted equally. These are just some of the influential factors that urged the Congress to pass the Minority Health and Health Disparities Research and Education Act of 2000, in November 2000, to create the NIH's newest Center, the National Center on Minority Health and Health Disparities. The official launching of the Center took effect in January 2001. Now, a little over one year old, I would like to share with you what we have been doing to implement the law and address the elimination of health disparities. For the benefit of those of you who may not be familiar with the law, let me briefly tell you what the Congress has asked us to do.

According to Public Law 106-525, the National Center on Minority Health and Health Disparities is authorized to lead, coordinate, support and assess the NIH effort to reduce and ultimately eliminate health disparities. The law also broadened the scope of the NCMHD's constituency to include other health disparity populations, such as the medically underserved. The Center's statutory priority must be Minority Health Disparities Research. To carry out these provisions, the Center has to implement three core programs --a Loan Repayment Program, an Endowment Program and a Centers of Excellence Program, as well as take the lead to develop a trans-NIH Comprehensive Strategic Research Plan and Budget to reduce and ultimately eliminate health disparities.

Many of you are familiar with our predecessor the Office of Research on Minority Health, which for 10 years served as the foundation within the NIH to systematically address minority health issues. As an Office, we worked with the NIH Institutes and Centers, community organizations and other federal agencies to identify research gaps and then applied our findings to create science. We realized the complexity of the issues and the multi-dimensional approach needed to ensure resolution, and through many of our partnership efforts, we were able to effect positive results which included the establishment of about 100 health-related projects and support to approximately 30 research training programs, such as the "Bridges to the Future" program with the National Institute of General Medical Sciences.

Other partnership projects undertaken with NIH Institutes and Centers include:

- **The African-American Study of Kidney Disease and Hypertension and the Minority Organ and Tissue Transplant Program, with the National Institutes of Diabetes and Digestive and Kidney Diseases;**
- **The development of research relationships between minority medical schools and the NCI Comprehensive Cancer Care Centers, in collaboration with the National Cancer Institute; and**

The ORMH collaborative activities expanded beyond the NIH ICs. The Office also worked with other Department of Health and Human Services agencies including the Office of Minority Health, the Centers for Disease Control and the Agency for Healthcare Research Quality. With the Office of Minority Health, ORMH supported projects such as:

- **The Asian and Pacific Island American Health Forum, and**
- **The National Medical Association's Mazique Symposium, as well as programs of**
- **The Association of Asian Pacific Community Health Organizations;**
- **The Association of American Indian Physicians;**
- **Quality Education for Minorities and**
- **The National Alliance for Hispanic Health.**

The Office succeeded by working collaboratively at various levels to unveil the gaps,

develop innovative projects to bridge those gaps, evaluate the outcomes and ultimately translate the outcomes into programs. The Center will continue to build upon these activities and this collaborative philosophy.

Over the past year, the NCMHD has worked diligently with its partners, the other Institutes and Centers (ICs) and Offices at NIH, to implement the statute. I am grateful for the extensive support and cooperation that the Center has received from Dr. Ruth Kirschstein, former Acting Director of NIH, and all of the other IC Directors. The help of the other ICs is demonstrated in the Center's achievements that I will discuss. In FY 2001, we were appropriated a total of \$132,044,000.00 to assume our activities. I am pleased to inform you that we have implemented all of our core programs authorized by Congress, developed the draft Trans-NIH Comprehensive Strategic Research Plan and Budget to Reduce and Ultimately Eliminate Health Disparities, solidified our organizational structure, hired new staff, co-sponsored several projects with other NIH Institutes and Centers and created the Center's website which can be accessed at www.ncmhd.nih.gov.

NIH COMPREHENSIVE STRATEGIC RESEARCH PLAN AND BUDGET

For the first time in the history of the National Institutes of Health, it will have a comprehensive Strategic Research Plan and Budget that will be a guiding mechanism for the conduct and support of all NIH minority health disparities research and other health disparities research activities. NCMHD was honored to be charged with the development

of this plan in collaboration with the Director of NIH and the Directors of the other NIH ICs.

The Plan was developed with substantial input from various stakeholders including the public, academia and health professionals, representing those populations who disproportionately experience disparities in health. It describes current activities and future plans of the NIH to address the health disparities crisis, to build a culturally competent cadre of biomedical and behavioral investigators and to increase the number of minority clinical and basic medical scientists who are essential to the success of our efforts.

There are three main goals of the plan -- research, research infrastructure and community outreach which encompasses information dissemination and public health education. Within each goal there are areas of emphasis and objectives to accomplish the priorities identified. Each objective outlines an action plan, time-line, performance measures to monitor and report progress and outcome measures to demonstrate accomplishment and ultimate impact. The Plan will continue to be an evolving document over the next five years. Once finalized, it will be posted on the NCMHD website on a continuing basis, and comments from the public will be welcomed. We will update and revise the Strategic Research Plan and Budget annually with the continued collaborative input of the other NIH ICs, and we will provide annual reports on our progress.

NCMHD PROGRAMS AUTHORIZED UNDER P.L. 106-525

One of the new capabilities that the Center welcomes is the opportunity to award grants. The Center's Advisory Council was recently appointed to offer advice and serve as the second level of review for grant applications. The NCMHD established two grant funding programs in FY 2001 --the Loan Repayment Program and the Endowment Program for Section 736 (Public Health Service Act) Institutions. We have also recently launched another grant funding program, --the Project EXPORT Centers of Excellence Program. None of this would have been possible without the collaborative effort that the other NIH Institutes and Centers extended.

LOAN REPAYMENT PROGRAM

The National Center on Minority Health and Health Disparities created two loan repayment programs in fiscal year 2001 --the Loan Repayment Program for Health Disparities Research and the Extramural Clinical Research Loan Repayment Program for individuals from disadvantaged backgrounds. The Loan Repayment Program for Health Disparities Research is aimed at increasing the number of highly qualified health professionals in health disparity research careers, and focuses on basic, clinical, and behavioral research with priority given to biomedical research. The Extramural Clinical Research Program seeks to increase the number of highly qualified health professionals from disadvantaged backgrounds who pursue clinical research careers. Applicants to the

loan repayment programs must have a health professions degree, such as a M.D., Ph.D., D.O., D.D.S., or equivalent doctorate degree. Individuals completing their residencies, post-doctoral training, and internships may also apply.

I am pleased to report that the first round of loan repayment awards were made to 45 health professionals in FY 2001, eight months after the Center's creation. Twenty-eight awards went to the Health Disparities Research Loan Repayment Program, and seventeen awards to the Extramural Clinical Research Loan Repayment Program. Of the total 45 awards, 34 individuals were from a health disparity population, and 11 were Caucasians pursuing health disparities research. Health disparity populations consist of African Americans, Hispanics, Asians, Pacific Islanders, Native Americans, Alaska Natives and the medically underserved. The medically underserved are members of the general population, as well as racial and ethnic minorities who live below the poverty line and live in non-metropolitan rural areas where a high percentage of the counties are designated as health professional shortage areas. The breakdown of the 34 health disparity population awardees are as follows:

<u>Race/Ethnicity</u>	<u>Total</u>	<u>HDR-LRP</u>	<u>ECR-LRP</u>
African Americans	22	11	11
Native Americans	02	02	00
Asian Americans	04	02	02
Hispanic Americans	04	02	02

Caucasians 02 00 02

THE ENDOWMENT PROGRAM

The Center is fortunate to have had similar success in implementing the Endowment Program for Section 736 Institutions, as authorized by Public Law 106-525. These institutions are Centers of Excellence already established by the Health Resources and Services Administration under Section 736 of the Public Health Service Act. The purpose of this program is to facilitate capacity building for minority health disparities research and other health disparities research at institutions that have a demonstrated commitment to educating and training researchers from minority and health disparity populations. In FY 2001, the NCMHD made the first round of endowment awards to five institutions.

Additionally, the Center is preparing to make endowment awards to two institutions that participated in the FY 2001 competition, per the recommendation of reviewers. The Endowment Program is an on-going priority for of the Center. Presently, the Center is accepting applications for the fiscal year 2002 round of competition through June 17, and plans to issue awards in September.

CENTERS OF EXCELLENCE PROGRAM

The Centers of Excellence in Partnerships for Community Outreach, Research on Health

Disparities and Training (Project EXPORT) will be established at academic institutions with a significant number of students from racial and ethnic minority and other health disparity populations. These Centers will:

- Promote the conduct of minority health and/or health disparities research;
- Encourage the participation of members of health disparity groups in biomedical and behavioral research as well as prevention and intervention activities; and
- Build research capacity.

The NCMHD recently concluded a series of technical assistance workshops in Dallas, Texas; Morgantown, West Virginia; Birmingham, Alabama and Seattle, Washington, to inform the community about the program and the application requirements. Workshop presentations are available on the Center's website for interested constituents who could not attend the workshops. Applications are currently being accepted until May 24th. We plan to announce the FY 2002 awards in September.

COLLABORATIVE PROJECTS

As the NCMHD evolves, we remain committed to forging partnerships among disciplines, communities, individuals, and at all levels of our constituency. With the support of our

constituents within and beyond the NIH community, we are able to identify the issues and gaps in minority health and explore the approaches that would help to make health disparities a historical phenomenon. The NCMHD envisions an America in which all populations will have an equal opportunity to live long, healthy and productive lives. We will leave no one behind. Examples of recent collaborative project findings include:

- Just last month, the American Academy of Ophthalmology issued a press release on the findings of Project VER, which stands for Vision, Evaluation, and Research Project. This was a joint project of the NCMHD and the National Eye Institute, which revealed that open-angle glaucoma was the leading cause of blindness among a sample group of Hispanic Southern Arizona residents of Mexican descent.
- Last year, the Diabetes Prevention Program that we supported in partnership with the National Institute of Diabetes & Digestive and Kidney Diseases, showed that moderate diet and exercise are beneficial in delaying and possibly preventing type 2 Diabetes for people who are overweight and at high risk.

Other collaborative projects that the NCMHD supports with other NIH ICs include:

- The Innovative Approaches to the Prevention of Obesity Program with the National Institute of Diabetes & Digestive and Kidney Diseases, which is aimed at evaluating interventions to environmental factors that contribute to inappropriate

weight gain in children, adolescents and adults.

- The Overcoming Barriers to Treatment Adherence In Minorities and Persons Living in Poverty Program, in conjunction with the National Heart, Lung and Blood Institute. The program evaluates interventions to overcome treatment adherence among racial and ethnic minorities and people living in poverty faced with certain diseases.
- The Healthy Aging in Nationally Diverse Longitudinal Samples (HANDLS) program, with the National Institute of Aging, is a community-based research effort designed to evaluate normative age-related health disparities in minority and socio-economically diverse populations. The program uses a Medical Research Van to facilitate the participation of minority, medically underserved and socio-economically diverse subjects in age related clinical research.

These are just examples of the many collaborative projects that the Center is undertaking that hold much promise for the American people.

NEW INITIATIVES

NCMHD is excited about the opportunity to undertake new approaches to address health disparities. As highlighted in the FY 2003 budget, some of the projects that will be of priority to the Center include:

- The Virtual University Program: to improve training outcomes for students from minority and other health disparity groups, improve the transition from undergraduate to graduate programs and to independent investigators, and serve as a resource for continuing education and/or retooling for faculty at participating institutions.

- The Rural Poor and other Health Disparity Groups: the NCMHD will collaborate with the National Institute on Dental and Craniofacial Research (NIDCR) to support 1) planning grants for research to prevent or reduce oral health disparities, 2) pilot grants for research to prevent or reduce oral health disparities, and 3) research infrastructure and capacity building for participating institutions to reduce oral health disparities.

- Community Outreach: the NCMHD is committed to creating communication channels that lend themselves to the bi-directional, interactive nature of effective outreach. Accordingly, the NCMHD will divide its outreach efforts into three major objectives:
 - Outreach to Communities and their Community Based Organizations;
 - Outreach to Health and Social Service Professionals; and
 - Outreach to Health, Research and Social Service Institutions, Professional

Organizations, and the Business Sector.

- Mississippi Delta Project: with a medical research agenda for the Mississippi Delta Region, the NCMHD will concentrate on:
 - (1) Solidifying the organizational and technological network within the community to conduct research on health disparities;
 - (2) Increasing the level of involvement of community residents in health research;
 - (3) Facilitating the availability of culturally-appropriate health education material; and
 - (4) Establishing a base for involvement of small businesses with these entities.

CONCLUSION

The NCMHD is grateful to the Congress, the Administration, the NIH Institutes and Centers and to all of you for the overwhelming support that you have provided the Center in transitioning from the Office of Research on Minority Health, to the National Center on Minority Health and Health Disparities. I am proud of the progress that the Center has made over the past year in establishing its organizational structure and programs. The American people can now learn about the Center's activities and programs by accessing our website at www.ncmhd.nih.gov which is now averaging about 50,000 hits a month. Through continued and increasing collaborative ventures, NCMHD will work diligently to define the health disparity issue for every

American, and garner support to ensure the health of all Americans. Health disparities is an issue that transcends minorities and other health disparity populations, --it is everybody's concern and calls for shared responsibilities to effect permanent change.

Thank you again for the opportunity to speak with you today.

Mr. SOUDER. Thank you for your testimony and congratulations on being the first Director. There will never be another first Director, so it has to be tremendously satisfying; and I appreciate your leadership.

I have a specific question on HIV/AIDS. It is increasingly becoming more and more dominant in the African American and Hispanic communities. In fact, other groups have stabilized or dropped, but the number of black and Hispanic women becoming infected continues to increase each year.

What efforts are you making to address this epidemic, and why do you feel that the current efforts are failing, because in this area it's actually increasing?

Mr. RUFFIN. Well, as you know, Mr. Chairman, there is an office at the National Institutes of Health which deals specifically—Congress has mandated an office that deals specifically with AIDS research at the National Institutes of Health. And that office collaborates with all of the other centers at the National Institutes of Health and also collaborates with the new center, that is the Center on Minority Health and Health Disparities.

And also if it's—we have been able—there is a report, a new report, which I've just seen recently, that has come from that particular office that deals specifically with how they plan to address those specific issues. Clearly, they recognize that this has become of epidemic proportions within those communities that you just mentioned. And during a visit to—their Web site, I noticed recently, clearly points out a number of initiatives that go to the core of your question.

That particular office, as well as the NIH in general, is beginning to invest and expand funding in research infrastructure at minority institutions to increase capacity for support for HIV/AIDS research. We are also increasing a number of funded minority investigators, because we know that goes to the heart of it as well.

We need to get more minority investigators trained in those fields. I think that the AIDS loan repayment program is a good way of doing that, because what we do by supporting those individuals is that we're saying to professionals around the country that if you go into AIDS research, what we will then do is that we will pay back those big loans that individuals have incurred in medical school, and other health professionals, to deal specifically with that whole issue. And I think as we begin more and more to train that cadre of researchers and get the word out, we will begin to address those issues, and in a major way.

And there are a number of initiatives that are under way, and particularly in the Office of AIDS Research.

Mr. SOUDER. So let me see if I understand: In your office, would the loan repayment program be under your office even—and one of the things your goal would be is to try to address the HIV/AIDS question in the minority communities?

Mr. RUFFIN. One of the things that happened at the NIH, and specifically with the creation of the new Center—the AIDS loan repayment program has been at the NIH for some time, but it was an intramural program. Individuals wishing to study and to come and do research on AIDS would have to come to the NIH and do that research in our intramural program. With the creation of the

Center, we now have an extramural loan repayment program, which means that individuals, minorities as well as nonminorities, throughout the country who are doing research in these fields can do that research wherever they happen to be.

Whether those individuals are in Wisconsin or anywhere, anywhere else in the country, they can now do research in those various areas. So now we have what is called an extramural loan repayment program that will help us to address those needs.

The program sponsored by the Center also does something else, it's not just for MDs. It's for MDs, Ph.D.s, individuals in dentistry, osteopathic medicine. Because all of those health professional fields are going to play a role in our ability to eliminate health disparities. That's the new aspect that comes with the extramural loan repayment program that did not exist when we had the intramural, just the intramural loan repayment program at NIH.

Mr. SOUDER. Is there a similar overlap in your outreach programs?

Mr. RUFFIN. Yes. Also I should add to that now—the loan repayment program is a program now that is extended in all of the institutes and centers at NIH. All of the institutes and centers can participate in the loan repayment program at NIH. This is the first year, of course, that we've been able to do that.

Mr. SOUDER. Thank you.

Mr. Cummings.

Mr. CUMMINGS. Thank you very much, Mr. Ruffin, for being with us.

I want to go back to something that Congressman Davis talked about in his opening statement, when he was talking about the medical schools, African American, black medical schools. And it seems like this would be an ideal place, Howard and Meharry, to perhaps address these problems and at the same time do something for the students there, do something for the institutions.

It's my understanding, for example, that the Howard School of Nursing has a program with Yale.

Mr. RUFFIN. Right.

Mr. CUMMINGS. Apparently, they send 4th year, I guess, students from Howard to Yale for a month, about a month, a little bit over a month; and they then get introduced to, I guess it is, high-level research.

And it sounds like—when I heard you talking about research, I take it—I mean, is that the kind of thing that you're talking about also? I mean, these are nurses that would normally—in talking to the Dean at Howard, she tells me they would at the end of their 4 years just go on and begin to practice. But it opens up the door to research.

Mr. RUFFIN. Absolutely. By the way, the funding for that program comes out of the Center. So I'm pleased to take credit for that.

Mr. CUMMINGS. Wonderful.

Mr. RUFFIN. I must also say to you that partnering between minority and majority institutions is something that is highly encouraged.

But I also mention in my testimony the creation of Centers of Excellence, Health Disparity Centers of Excellence. These centers would be distributed all over the country.

You know, we have other kinds of disparities. As I listened to Congressman Davis talk about some of the situations in Arkansas, one of the other kinds of disparities that we have in our country is, "geographical disparities as well." So getting these centers located to various places throughout the country, I think, is going to help.

Many of the historically black colleges and universities will benefit from the creation of these centers because we have devised at NIH three different mechanisms to level the playing field. All of our programs are competitive programs, but institutions have to begin to compete on different levels. So we've created three different mechanisms for institutions to compete for these Centers of Excellence.

One is what NIH calls an R-25 mechanism, which is simply a planning grant. Institutions which may not be ready for a center can compete for the planning grant, 3 years, up to \$350,000 a year to plan for their centers.

Other institutions, we have a mechanism which we call a P-20; those are institutions—essentially an exploratory center. It's a corporate agreement. We hold hands with those particular centers to say, NIH is here. We're going to help you. We are going to be with you. We're going to walk until you are ready to go on your own.

Those centers, individuals will compete on those.

Then, of course, throughout the country we have institutions like Yale and others that we've invested in over the years that we want to also get involved in health disparity research. These are P-60's, and those institutions will be able to compete for health disparity grants as well. And so we are going to make those awards this September.

We have had what we call technical assistance workshops all around the country over the last few months to tell people how to compete, before the fact to give them the information and to let them know what the expectations are. And I know from the interest that we're going to get a number of institutions around the country competing for these programs.

Mr. CUMMINGS. I know that you don't have a crystal ball, but you are in a position where at some point around 2010 somebody is going to—a whole lot of people are going to probably say, well, back then a few years ago a goal was set for us to address these disparities effectively by 2010, and I mean, what do you see happening?

What do you—I mean, what obstacles are in your way from what you can see? And talk about money and talk about what we can do as the Congress to help you address these issues.

I just—you know, I couldn't help but just listen, and listening to Congressman Davis, I have two relatives, a grandfather and a grandmother, who I know died prematurely; and I never even got to know them. And so, you know, we talk about quality of life, we also talk about the quality of life of having that grandparent there for that grandchild. Because, you know—and it just—I don't know if a lot of people realize how serious this problem is because, going back to my question, what do—where do you see us in 2010?

Mr. RUFFIN. Mr. Cummings, I'm encouraged; and one of the reasons I'm encouraged is for the very thing that's happening here today, that is, your ability and the ability of this subcommittee to listen to those of us who have been out in the communities and have listened to the individuals who are affected most. At the NIH and certainly with the creation of the new Center, we've tried to establish a new paradigm. And I think this new paradigm is going to lead to some results that perhaps we didn't get in the past and we will get by 2010.

And that paradigm is this: What we're trying to do is to do what you're doing and that is to listen to the community. I mention in my statement that we go and we ask the community, what is it—and they're the ones after all who know best. We ask them, what is it that we should be doing that we're not doing. And when you give people a chance to talk, they generally tell you what it is that needs to be done.

What we have to do as professionals is take the recommendations that they give to us, bring it back to an organization, an agency like the NIH, the premier biomedical research facility in the world, and try to take those recommendations and convert them to good science. And that's what we are trying to do. And think if we do that, I think the result this time around is going to be different.

And so my perspective, looking through my crystal ball, is very favorable about what's going to happen as it relates to health disparities.

Mr. CUMMINGS. Just one last question. What's the relationship between NIH training programs that you were describing and those who—HRSA's Bureau of Health Professionals that aim to train minority clinicians; and is it a complementary relationship?

Mr. RUFFIN. HRSA has for some years, as you know, had the Centers of Excellence program. These are 736 institutions that were established in public law. They're not all minority institutions, some of them are research-intensive institutions, but a great deal of them are minority institutions.

The law that established the center has allowed us the ability to make loans—I'm sorry, endowments to many of those institutions; and funds from those endowments can be used for a multiplicity of purposes. Not all of those 736 institutions would qualify. It is the institutions among the HRSA Centers of Excellence that are doing good science, but that have small endowments. And we're concentrating on those institutions to give them the necessary resources to build a strong biomedical emphasis.

Mr. CUMMINGS. Again, we thank you for—under the circumstances, for being with us. And you know our spirit and our hearts are with you. And our prayers.

Mr. RUFFIN. Thank you.

Mr. SOUDER. Mr. Davis.

Mr. DAVIS OF ILLINOIS. Thank you very much, Mr. Chairman.

Dr. Ruffin, let me first of all congratulate you on your appointment, and I also would commend the appointing officer for making what I would think was a very wise selection.

Mr. RUFFIN. Thank you, sir.

Mr. DAVIS OF ILLINOIS. Your testimony actually is some of the most stimulating that I've heard in a long time in terms of possibilities for serious movement.

I also want to commend you on the program activity that has already been generated, especially the loan repayment which deals with a real issue and a real problem that people have.

And then the whole business of trying to train more minority researchers. I can tell you, I've participated in so many research projects where we first had to train the principal investigators until I just got tired of it; you know, I'm saying this is ridiculous that these are the people who are in charge, and we've got to train them. And so I'm so pleased to see that.

And also I'm pleased to see that there would be some focus on trying to engage the historically black colleges and universities more into the activity. I think that we've made a tremendous amount of progress.

When we had the old health rights programs when we really saw health in a big way in communities, still many of the people that we're talking about are poor. I mean, many of the people with the greatest amounts of disparity, notwithstanding the fact that there are some other people that have some too, but poor people. And it seems to me that poor people require certain kinds of help and process; and you mentioned outreach, and that's my question.

When there was a great deal of outreach, I thought we were making serious progress. But then we killed off that activity prematurely, again, I think when we killed off the old OEO program and activities.

And how prominent do you see outreach becoming as a part of the focus of the Center as we deal with the disparity question?

Mr. RUFFIN. It's a major part. And not only that, but I mentioned to you that we ask people constantly, what is it that we ought to be doing that we're not doing. And this is one of the issues that come up often. And there are several ways that we're going to try and do these kinds of things over time.

One, of course, is, as I said, trying to develop the centers in strategic places around the country. But in addition to that, one of the other issues that has been raised prominently is the role of community and community-based organizations, all in all, of what we do.

I have to say that at NIH is one of those; that's one of those areas where there is a gap, and that is the participation of community-based organizations. We've had some activities where community-based organizations have participated with academic institutions in various partnerships. But there, terms of developing a role, a very significant role, for community-based organizations, I think that would enhance to a great extent our ability to do effective outreach. And we're going to continue to develop some programs in that area as well.

The community is demanding that we develop some programs in that area. So we have an office in the new Center that is devoted exclusively to outreach and a relationship with community-based organizations and trying to address that very issue that you're mentioning.

Mr. DAVIS OF ILLINOIS. Let me just thank you very much. Your words to my ears are like manna from heaven, because I don't be-

lieve that you could do a lot of things for people, that you have to do things with people. And if you get people engaged and involved and have you them moving in concert, then I think you can see some progress.

And so, you give me a great deal of hope. And I certainly look forward to working with you and hope that we can move this process along.

And I thank you very much, Mr. Chairman, and yield back.

Mr. RUFFIN. Thank you, sir, and thank you for allowing me to testify today.

Mr. SOUDER. Thank you, Dr. Ruffin. You're free to leave. We appreciate once again that you stayed today.

Mr. SOUDER. Next, we move to the testimony from Dr. Stinson.

Dr. STINSON. Good afternoon. I am Nathan Stinson, the Deputy Assistant Secretary for Minority Health and the Director of the Office of Minority Health in the Department of Health and Human Services. I thank you for the opportunity to testify before the subcommittee today.

As has been previously stated, it is very clear that health disparities are not a new occurrence. In fact, the 1983 issue of Health, United States, which is the annual report card on the health status of the American people, documented that, although significant progress had been made in the overall health picture, there still were persistent and chronic disparities experienced by racial and ethnic minority populations versus the United States as a whole.

During the final evaluation of Healthy People 2000, where the experts in the different health fields testified about the progress made over the past decade, almost without exception they talked about how the health in general had improved but how disparities among racial and ethnic minorities had either persisted or in many cases had gotten worse over the past decade.

This hearing, as Dr. Ruffin said, could not be more timely. There are many efforts that are occurring not only within the Department of Health and Human Services but also in State and local communities to address a problem that we know will not go away unless we give it direct and focused attention.

The Department of Health and Human Services is currently involved in a process of developing a comprehensive overall plan to address and to marshal the assets that it has in all of the different agencies to address the disproportionate burden of illness on racial and ethnic minority populations. The Office of Minority Health, because of its role as the adviser to the Assistant Secretary of Health and the Secretary in health-related matters as they affect racial and ethnic minority populations, has the opportunity to play a very key role in shaping not only the policy aspects on how to address these problems but also the implementation of any of the particular programmatic activities within the Department.

I am going to talk very, very quickly about five specific areas as ways that the Office of Minority Health implements its programs or influences the Department in its programmatic development and implementation. The five areas are not in any particular order of priority, but I want to start out by talking about strategic communication and information dissemination.

It is very, very clear that it is important to develop the appropriate health messages, to deliver those messages in a way that individuals are receptive to and, as importantly, to gauge how effective we have been in producing an enhanced knowledge base and sometimes a change in any particular behavior.

The Office of Minority Health has periodic communications that it makes available to over 10,000 organizations and individuals. We have a Web site that is available for organizations and the public at large, and we have also tried to enhance the capacity of the resource center from a science and research capability to try to provide the opportunity to create a one-stop shopping place for organizations and for individuals who have any interest in the areas of minority health.

One of the specific and new activities is a partnership that we have at ABC Radio with their urban network radio stations around the country where the Department of Health and Human Services is providing ABC Radio with the medical content and the messages that they then play on their affiliates around the country at no cost to the Department, but it is a very important way to reach the population at large.

Clearly, the Department cannot do this by themselves. Partnerships are crucial to addressing the problems of health disparities around this Nation. We work closely with State departments of health. Many of them have offices of minority health and have formed a minority health network where we work very closely with the efforts that are occurring within individual States and minority communities.

It is very, very important, as Dr. Ruffin said, that the recommendations, the program development, the implementation are really based on good science. So the Office of Minority Health, because it has a direct appropriations, is also able to fund some demonstration programs to test some innovative ideas and test out some different opportunities, outreach to minority communities and then try to help translate some of the lessons learned and some of the models that work into the broader categorical programs within the Department.

One of the last two areas I want to talk about is policy development. Clearly, it is very crucial, as we look at how effective our programs are in attaining the outcome we are interested in, is that we make sure that any type of particular policies that we have do not create any barriers to what happens at the State and local level, but, more importantly, that we actually have a systematic way of policy development and implementation that actually enables the actions that are necessary to address health disparities to occur and, therefore, are very proactive in overcoming any perceived barriers that are there.

Last is the collection of racial and ethnic data. This area is extremely important. It is important that we understand where the potential problems are, but it is also important in that we have complete and comprehensive information so that we know whether or not we are actually producing the outcome we want, we know whether or not it is time to change what we are doing because the application of those resources are not going to likely deliver the output that we are interested in, and that we also know what other

areas of disparities are starting to develop in any other particular group or any other particular condition.

As Dr. Ruffin said, quite directly and very completely, this is a very unique time that we have to step back and really look at what is it that we need to do to keep this Nation healthy and strong, what do we need to do now as we look at the objectives and goals that we have for Healthy People 2010, what do we need to do now to assure that the investments that we make as a Nation are going to give us and allow us to reach that ultimate outcome at the end, which is a healthier Nation.

Thank you again for the opportunity to testify before the subcommittee.

Mr. SOUDER. Thank you.

[The prepared statement of Dr. Stinson follows:]



Testimony
Before the Subcommittee on Criminal Justice,
Drug Policy, and Human Resources,
Committee on Government Reform
United States House of Representatives

**OMH's Role in Eliminating Racial and
Ethnic Disparities in Health**

Statement of

Nathan Stinson, Jr., Ph.D., M.D., M.P.H.

*Deputy Assistant Secretary for Minority Health,
Office of Public Health and Science
U.S. Department of Health and Human Services*



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INTRODUCTION

Good morning. I am Dr. Nathan Stinson, Deputy Assistant Secretary for Minority Health and director of the Office of Minority Health (OMH). I want to thank Chairman Souder, Mr. Cummings, and the respective members of the Criminal Justice, Drug Policy and Human Resources Subcommittee of the House Government Reform Committee for the invitation to testify at this important hearing on the Department of Health and Human Services' (HHS) status and progress towards eliminating racial and ethnic health disparities.

BACKGROUND

It is clear that health disparities are not new occurrences. The 1983 issue of *Health, United States*, the annual report card on the health status of the American people, documented significant progress in the overall health picture of the Nation, but reinforced the sad fact of the continuing health-related burdens experienced by the racial and ethnic minority populations compared to the U.S. population as a whole. Such health disparities continue to persist:

Although 55 percent of the reported AIDS cases occurred among African Americans and Hispanics, these two populations groups represent approximately 13 and 12 percent, respectively, of the total U.S. population. Similarly, 15 percent of the U.S. adolescent population is African American, yet 60 percent of the AIDS cases reported in 1999 were among African Americans.

On average, Hispanic/Latino Americans are almost twice as likely to have

diabetes than non-Hispanic whites of similar age. American Indians are at least twice as likely to have diabetes compared to non-Hispanic Whites of similar age.

Data on the number of Asian and Pacific Islander Americans who have diabetes are limited, but studies show that type 2 diabetes is a growing problem among some groups within this population. For example, the prevalence of type 2 diabetes is two to three times higher among Japanese Americans living in Seattle compared with non-Hispanic Whites and two times higher among Native Hawaiians compared to White residents living in Hawaii.

African American women -- those with less than, equal to, or greater than 12 years of education -- suffer at least twice the incidence of infant mortality compared to either White or Asian and Pacific Islander women.¹

¹ Health, United States, 2001, Table 21 (1996-1998), page 154.

Between 1980 and 1990, there was almost a 40 percent increase in obesity among adults aged 20 years or older in the general population.² Adult (20-74 years) Black, non-Hispanic female have a higher incidence of overweight and obesity compared to White, non-Hispanic females.³

Unfortunately, those communities experiencing disparities are hardest hit. They suffer worse health status and higher episodes of mortality, and this is unacceptable. The real challenge for HHS and the public is not debating whether disparities exist, but in developing and implementing strategies to reduce and eliminate them.

This hearing could not be more timely. There are multiple cross-cutting activities going on within HHS to make progress towards eliminating racial and ethnic health disparities. Further announcements of some of these activities will involve not only HHS, but the state and local governments, private sector, and communities as well.

OMH has taken an advisory and leadership role in the Department's coordinated efforts that relate to disease prevention, health promotion, and improved access to quality health care for the underserved populations. The OMH advises the Assistant Secretary for Health on public health issues affecting the diverse populations and is key staff for major Departmental initiatives directed towards

² Testimony by Frank Vinicor (August 13, 2001) before Senate Finance Committee chairman, Max Baucus (D-MT).

³ Health, United States, 2001, Table 69 (1988-1994), page 256.

improving the health of racial and ethnic minorities. The Office of Minority Health does not have direct line of authority -- authorizing legislation requires the PHS agency heads to consult with the Deputy Assistant Secretary for Minority Health to coordinate activities to improve minority health.

OMH's mission is to improve the health of racial and ethnic minority populations through the development of health policies and programs that will help to address health disparities and gaps. This mission is even more important in light of the increasing racial, ethnic, cultural, and linguistic diversity of the U.S. population, the major changes underway in the health care industry, and the challenges of adequately addressing the health care needs of the U.S. while controlling the associated costs.

To work towards the Department's goal, OMH strives to encourage these changes to improve and strengthen the public health infrastructure by advocating for the improvement of communication and information dissemination, policy coordination and development, coalition and partnership building, demonstration programs and program evaluations, and data collection and analysis. OMH assesses the impact of proposed policies, programs, legislation, and changes in the health care delivery system on racial and ethnic minorities' health, coordinates evaluations and reports to Congress for OMH, coordinates efforts to improve the availability and quality of health data for minorities, reviews agency budget requests, and staffs inter-departmental committees.

OMH ACTIVITIES

Communication and Information Dissemination

OMH is an integral part of the Department's voice in spreading the message on how to prevent disease, disability and death through the dissemination of information on racial and ethnic minority health, such as up-to-date facts and resources, scheduled conferences and events and campaign information, to name a few. The goal is to keep these issues on the radar-screen in order to lay the foundation for responsive policy and program action.

OMH is engaged in departmental-wide campaigns to promote disease prevention, awareness, and preventive actions in the public. These efforts will depend upon partnerships within HHS and other departments, as well as state and local governmental agencies, and non-governmental and private entities, such as national and community minority organizations and faith-based organizations, to name a few.

Closing the Health Gap, the new HHS partnership with ABC radio network, was launched early in FY2002. This strategy will reach African American consumers about the health gaps between them and the rest of the population, and to challenge and empower them to make lifestyle behavior changes to help close the gap.

This past April, OMH was engaged in the kick-off of "Take A Loved One To The Doctor Day." Designated as Sept. 24, 2002, "Take A Loved One To The Doctor Day" will rally African-Americans—and really, the Nation as a whole—to visit a health professional or

make an appointment to see a health professional. This is designed to encourage African-Americans and other minorities to become more involved in their health care and health choices by working with local organizations and ABC Radio Networks' urban affiliates to help set up appointments with health care professionals and to accompany them on visits to the doctor. HHS and ABC hope to encourage hundreds of fraternal, social, religious, health and community-based organizations, local health departments, and radio stations to take part in "Take A Loved One To The Doctor Day" by organizing screenings, health fairs, and other events promoting health and wellness. ABC Radio Networks' Tom Joyner, nationally syndicated radio personality and host of the Tom Joyner Morning Show, co-chairs the national campaign.

Since its inception in 1987, the Office of Minority Health Resource Center (OMH-RC) has grown to become one of the nation's largest sources of minority health information. The OMH-RC collects, distributes, and facilitates the exchange of information through customized database searches (including funding, media, research, and data information), publications, mailing lists, and referrals. To reach the diverse population, bilingual (Spanish/English) information specialists as well as translated written materials are available.

OMH has continued to produce high-quality and highly-sought-after publications that appeal to consumers, universities, state offices of minority health, health educators, researchers, and administrators. The OMH-RC develops and distributes two OMH newsletters, each of which has a circulation of more than 40,000.

Closing the Gap is published 10 times per year and covers a different minority health topic each month. It covers both the successful efforts of minority community programs working on health issues, and services/resources available from HHS agencies. OMH has closely collaborated with CMS, AoA, HRSA, CDC, ODPHP, OWH and other agencies to develop a number of special issues focused on key health topics for minority audiences. Recent issues have been on men's health and violence prevention and the upcoming issue is on diabetes.

- The second newsletter, *HIV Impact*, appears four times per year and focuses on information community-based and AIDS-service organizations can use in their work.

OMH continues to update *The Pocket Guide to Minority Health Resources*, the single most requested publication originated by OMH. The popular *Breast Cancer Resource Guide for Minority Women* was also reprinted by OMH. Now in its second edition, the publication contains a wealth of resources for minority women with breast cancer, their families, and health professionals who treat breast cancer.

Web-sites have become a major source of information to learn about new facts, legislation and conferences, to name a few. In FY 2000, OMH launched its new and improved web site (www.omhrc.gov). Administered by OMH-RC, the site contains information on minority health, including pages on: what's new, programs and initiatives, data and statistics, funding opportunities, conferences, legislative action in Congress, and useful information links. Hits

on the website are expected to increase from 1 million in FY 2000 to a projected 3.2 million in FY 2002. This website includes a Departmental *Hispanic Agenda for Action* web site, building upon the work of the HHS Hispanic Customer Service Pages. OMH coordinates HHS's efforts to implement other selected White House Initiatives, and is developing the *Historically Black Colleges and Universities*, and *Tribal Colleges and Universities* sites. OMH also developing a cultural competency web site that contains complete information about the national standards for culturally and linguistically appropriate services (CLAS) in health care.

OMH-RC launched a website dedicated to the Department's Minority HIV/AIDS Initiative. This web site provided information on current news, funding, technical assistance, prevention and living with HIV/AIDS, and included links to reports, archives, and both federal and non-federal sites. A special page on the 20th anniversary of the first reported cases of AIDS was created in May 2001 and provided a tool kit for local organizations to plan and implement commemorative efforts. This special page received more than 10,000 hits in its first two months of operation.

Under the Minority HIV/AIDS Initiative, the OMH-RC expanded technical assistance to minority community-based organizations (CBOs) and AIDS service organizations (ASOs). This HIV/AIDS technical assistance and services team works to increase awareness of HIV/AIDS among minorities and support organizations that service racial and ethnic minorities. A national technical assistance campaign was conducted in six cities, focusing on

organization development and sustainability of CBOs and ASOs. Nearly 750 persons representing 168 organizations participated in skills building workshops. Direct technical assistance site visits to an additional 35 organizations, and telephone and mail consultations with another 40 organizations were provided.

The OMH-RC also promotes and educates the public on minority health issues by representing OMH at national conferences of professional organizations, hosting workshops and exhibits, working with the other HHS agencies to publicize special health promotion campaigns, and initiating its own media projects that improve the quality and availability of health information to minority communities. In addition, OMH-RC initiates its own media projects that improve the quality and availability of health information to minority communities. In FY 2000, OMH developed and conducted a national print media campaign targeting African Americans to increase HIV/AIDS awareness among this population. The campaign generated inquiries from around the Nation requesting OMH-RC's HIV/AIDS information packets.

Policy Coordination and Development

Because culture and language are vital factors in how health care services are delivered and received, it is important that health care professionals embrace the principles of cultural and linguistically appropriate care. OMH has initiated a project to develop Cultural Competency Curriculum Modules for family physicians. This is a two-year

project and will result in the development of modules to equip family practitioners with the cultural and linguistic competencies that will enable them to better treat the increasing diverse U.S. population.

As required by the Health Professions Education Partnerships Act of 1998 (P.L. 105-392) OMH provides staffing and resources to HHS's Advisory Committee on Minority Health. This newly formed Advisory Committee will provide recommendations to the Secretary and Department on issues related to minority health and health disparities. The Committee comprises twelve (12) members who are not employees or officers of the Federal Government. The Committee meets four times a year and all sessions are open to the public and announced before hand in the Federal Register.

The 1990 Disadvantaged Minority Health Improvement Act (P.L. 101-527) and the Health Professions Education Partnerships Act of 1998 (P.L. 105-392), require the OMH to address each of the four racial/ethnic populations identified in the legislation equitably. Prominent activities of the OMH include leading and staffing White House and Department Initiatives aimed at improving the ability of the Federal government and educational institutions to serve racial/ethnic minorities.

The minority initiatives are designed to strengthen the capacity of institutions of higher education, and community-based organizations that serve minority populations, to

provide a quality education, develop researchers and address the health and human service concerns of racial/ethnic minorities. The minority initiatives' activities have assisted the Department in its efforts to change the way it does business in several key areas, including the elimination of racial and ethnic disparities in health. The Department has institutionalized specific activities aimed at fulfilling the mission of the minority initiatives, including: strengthening partnerships with institutions of higher education; increasing Hispanic employment in the Department; improving customer service, and a mechanism to increase the funding for institutions of higher education that are effective at enrolling and graduating minority students.

OMH coordinates activities to support the Hispanic action agenda, inclusive of Executive Order 13230, President's Advisory Commission on Educational Excellence for Hispanic Americans. This is a nine-point agenda which addresses issues of employment, educational opportunities, capacity building, data collection and research, and health. The broad goal of this initiative is to strengthen the Department's efforts to improve service delivery for Hispanic customers and improve their overall well-being.

OMH has leadership responsibility within the Department for managing, coordinating and monitoring activities required under Executive Order 13256- Historically Black Colleges and Universities (HBCUs.) This Executive Order requires all Federal agencies to strengthen the capacity of HBCUs to provide quality education, and to increase opportunities to

participate in and benefit from Federal programs.

In this capacity, OMH provides technical assistance to Department agencies and offices regarding implementation of the Executive Order and to HBCUs regarding program activities in which they might participate.

Executive Order 13125, Increasing Opportunity and Improving Quality of Life of Asian Americans and Pacific Islanders, is aimed at improving the quality of life of Asian Americans and Pacific Islanders through increased participation in Federal programs where they may be underserved (e.g., health, human services, housing, education, labor, transportation, and economic and community development). Based on the pioneering work of the HHS's AAPI Action Agenda, this executive order establishes an advisory commission and a White House Initiative on AAPIs. OMH has led the Department in the development of a snapshot of departmental programs, an inventory of departmental efforts targeted to AAPIs, and is in the process of refining HHS's FY2002 agency plan for implementing the executive order.

The White House Initiative on Tribal Colleges and Universities, pursuant to Executive Order 13021, reaffirms the special relationship of the Federal government to American Indians and Alaska Natives. **The initiative aims to increase the Tribal Colleges' access to Federal opportunities, expand their participation in Federal programs, and raise awareness about the important role TCUs have in Tribal communities. The order also fosters**

links between TCUs and both private and non-profit organizations.

In this capacity, the OMH provides technical assistance to Department agencies and offices regarding implementation of the Executive Order, and to TCUs regarding program activities in which they may participate.

Quality Improvement Activities—In February 2000, OMH/OPHS convened the meeting on *Diversity and Communication in Health Care: Addressing Race, Ethnicity, Language and Social Class in Health Care Disparities*. The goal was to determine the state-of-the-art for improving provider-patient communication, determine its adequacy to raise effectiveness of health care for racial and ethnic minorities, and develop a work plan to provide needed modifications. The meeting brought together health professions educators, practitioners, patients, and community representatives. More than 80 invited experts in patient provider communication, cultural competency, and health professions education participated in the meeting. A summary report was distributed to participants.

Coalition and Partnership Building

Partnerships with fellow HHS agencies and other Federal departments, representatives from state and local government, community-based organizations, and the public in general is critical in making progress. Making the bridge with the communities and resources allows us not to reinvent the

wheel. We are able to know rather than assume what problems they face, what's been done, and what has worked.

OMH has been crafting and leading the development of HHS's *National Leadership Summit on Eliminating Disparities in Health Among Racial and Ethnic Minority Populations*. This Summit is scheduled for July 2002 in Washington, D.C. The Summit seeks to draw national attention to the existence of health disparities and to the innovative approaches being implemented at the local, state, and Federal levels to address these disparities. The aim of the Summit is to stimulate replication of programs and to enhance program outcomes. Approximately 2,500 leaders of national, state, and community-based organizations representing all sectors that influence health (e.g., housing, labor, education) will attend. The Summit will emphasize the critical need for all groups and organizations to work together and across all sectors to improve the health of our communities. The Summit is also designed to impart skills to individuals who can then use them as a means to enhance efforts within their own communities.

To ensure that participants leave the Summit with tangible information and resources that can be used in their communities upon their return, OMH is developing a community resources "Tool Box" to serve as a resource for individuals and organizations looking to enhance their programs or to start new programs.

OMH is also sponsoring, "*A National Forum on Health Disparity Issues for American*

Indians and Alaska Natives: Breaking Down Barriers - We are all Related, " a forum for Tribal leaders, Urban Indian health organizations, health officials, federal and state policymakers, and public/private organizations to jointly work on eliminating barriers that perpetuate health disparities for American Indian/Alaska Natives. This forum is directed to not only identify strategies and foster partnerships among federal, state, local and tribal governments to fulfill their obligations to improve the health status of all American Indians and Alaska Natives, but to also recognize and honor the legal and historic basis for tribal sovereignty, trust responsibility, and government-to-government relationships in these strategies.

OMH has linked Federal, public and private sector groups, community-based organizations, and individuals to exchange information and coordinate activities on health status and the quality of life of racial and ethnic minority populations. This *Minority Health Network* focuses on developing a Federal and State infrastructure. **Offices of Minority Health have been established in OPHS, NIH, HRSA, CDC and SAMHSA. Minority health coordinators/contacts have been designated in, AoA, ACF, CMS, FDA, AHRQ, and IHS. The Network also includes the 10 OMH Regional Minority Health Consultants and 34 State minority health entities.**

The OMH-RC makes available the Resource Persons Network, which consists of a network of health professionals from a wide variety of organizations (e.g., community organizations, academia, research organizations, medical centers) who volunteer to provide technical

assistance to community-based organizations and other health professionals active in minority health issues.

The OMH held a meeting of the State Minority Health Representatives in September 2001. Directors from existing State offices of minority health, and minority health contacts in States (including the District of Columbia, Puerto Rico, and the Virgin Islands) which do not have a formal minority health structure, attended this summit. This summit was designed to: (1) provide state minority health representatives with the information and guidance needed to meet the challenges of emerging health-related issues impacting the states and the communities they serve; and (2) provide a forum for developing strategies and fostering collaborations and partnerships that will address health-related issues in a concerted effort to eliminate health disparities across the nation.

Under the State Partnership Initiative, the OMH awarded contracts to 12 State minority health entities in FY 2000. In early FY 2000, OMH completed an assessment of State minority health infrastructure and capacity to address health disparities. The study's recommended strategies that, if addressed in their entirety, could lead to substantial improvements in efforts at the state level to address racial and ethnic health disparities. These recommended strategies include: collection, tracking, and dissemination of data; improving inter- and intra-organizational collaborations related to minority health; technical assistance to improve state health infrastructures; and funding for minority health initiatives at the state and local levels. In FY 2001, OMH began to implement a number of the study recommendations, including awards to four State minority health entities and funds to the 10

PHS Regional offices.

Foster research demonstrations, scientific investigations, and evaluations aimed at improving the health of racial and ethnic minorities

To fulfill OMH's role in supporting demonstrations and evaluations to test innovative models, and to increase access to services for persons with limited English proficiency (LEP), OMH supports a number of grant programs and cooperative agreements aimed at developing innovative approaches to eliminate racial and ethnic health disparities. Grant projects include: efforts to improve and expand the capacity for linguistic and cultural competence of health care providers, health promotion and disease risk reduction interventions, community-based HIV/AIDS education and prevention activities, and provision of technical assistance to stimulate and foster the development of effective and durable service delivery capacity for HIV prevention and treatment among organizations which are closely interfaced with minority populations highly impacted by HIV/AIDS.

As directed by FY 2001 appropriations language, OMH provided one-year funding to 11 organizations to conduct activities initiated by each organization. For example, the Donald R. Watkins Memorial Foundation in Houston, Texas, will enhance care for African American and low income individuals with HIV/AIDS by coordinating services and expanding outreach efforts. The Fresno Community Hospital and Medical Center of California will support diabetes care and outreach for Hispanic Americans and low-income

individuals. FY2002 appropriations language also directs the supports of 11 organizations (10 new, one continuation.)

OMH has continued to support its principal demonstration grant programs: the *Bilingual/Bicultural Service Demonstration Program* to improve the ability of health care providers and other health care professionals to deliver linguistically and culturally competent health services to limited-English-proficient minority populations; and the *Community Programs to Improve Minority Health Grant Program* (formerly, the *Minority Community Health Coalition Demonstration Program*) which supports projects that address socio-cultural barriers and demonstrate effective coordination of integrated community-based screening, outreach, and other enabling services.

In FY 2001, OMH funded 30 grants under the newly established *Health Disparities Grants in Minority Health Program* to support local pilot and small-scale projects which address a wide range of health problems and issues related to health disparities in local minority communities.

In FY 2001, OMH has continued the Programs funded by the Minority HIV/AIDS Initiative, the *Technical Assistance/Capacity Development Demonstration Program (TA/CD) for HIV/AIDS-Related Services in Highly Impacted Minority Communities, State and Territorial Minority HIV/AIDS Demonstration Program*, and the *Minority Community Health Coalition Demonstration Program HIV/AIDS*. Continuation support was provided to 37 grantees in

FY 2001.

OMH has continued to support and manage umbrella cooperative agreements and standard cooperative agreements. The umbrella cooperative agreements establish broad programmatic frameworks for multiple projects. Cooperative agreements have been used to provide an opportunity for HHS and other federal agencies to collaborate and jointly fund individual projects.

OMH currently has 27 multi-year cooperative agreements to assist in enhancing and expanding health promotion, disease prevention, health advocacy and health services research opportunities within minority communities. OMH also has a cooperative agreement with Central State University to support a Family and Community Violence Prevention Program at HBCUs and other institutions. Participating institutions partner with community organizations to influence the academic and career development of at-risk populations, improve the quality of life for residents of impoverished neighborhoods which surround many campuses, and reduce the potential for violent behavior among youth and their families. A cooperative agreement with Cicatelli Associates, Inc. supports an HIV/AIDS Regional Resource Network Project. This project focuses on improving coordination, comprehensiveness and quality of HIV/AIDS service provision by bringing community-based organizations, primarily those providing support services to communities of color, into federal regional planning and networking efforts.

Promote the Collection of Health Data by Racial/Ethnic Categories

Lack of data places policy makers at risk of making inappropriate decisions that reflect a lack of understanding of the mechanisms driving the increased burden of disease and death as well and its impact. The absence of timely, reliable, valid, and appropriate data is often a limiting factor in measuring progress of programs and status of the targeted population.

Creative efforts have taken place within HHS to meet data challenges. For example, DHHS has organized a Data Council that plays a role in a number of areas, particularly in the development of department-wide data collection, to which Assistant Secretaries and Agency Administrator level DHHS officials have a direct reporting relationship to the Secretary.

The OMH co-chairs the HHS Data Council's Working Group on Racial and Ethnic Data, the internal advisory group to the Secretary on minority health data and statistics. Major accomplishments of this Working Group include an inventory of HHS data collection systems which make their data available to the public (<http://www.aspe.os.dhhs.gov/datacncl/datadirectory>), a report *HHS Plan to Improve the Collection and Use of Racial and Ethnic Data* which outlines data gaps and makes recommendations to improve racial and ethnic data across HHS, and an HHS inclusion policy for racial and ethnic data in HHS sponsored and maintained data systems.

In August 2001, the Data Council's Working Group on Racial and Ethnic Data planned and

OMH sponsored two sessions at the American Statistical Association annual meeting to showcase the Department's efforts to further racial and ethnic data policy as well as efforts at the state and local levels. For the session on "Improving Data on Racial/Ethnic Groups," panelists described successful efforts involving the communities studied. For the session on "How to Implement Racial/Ethnic Data Policy," panelists discussed policy issues as well as innovative approaches for improving racial and ethnic data collection, analysis, and dissemination.

OMH continues to provide technical assistance on racial and ethnic data to HHS, other Federal and state agencies, and non-Federal entities. For example, during FY 00 and FY 01, OMH participated in the Academic Medicine and Managed Care Forum's Subcommittee on Minority Health. The Forum, the largest private sector funding source of health services research, has established health disparities as a priority.

During FY 2001, significant progress was made to develop and pilot test a uniform information/data set for evaluating and assessing the impacts of OMH-funded activities. OMH is completing the final report and guidelines to implement uniform data collection, reporting, and analysis among OMH-funded programs.

In FY 2001, OMH's contractor, National Health Law Program, completed an initial review of state laws, regulations, and other written policies regarding the collection, reporting, and use of racial and ethnic data in the health care context among all 50 states and the District of

Columbia. The findings will be critical in clarifying state policies on the collection of racial and ethnic data. **Preliminary results of this project have found that 46 states do not prohibit health insurers and/or health maintenance organizations from collecting racial and ethnic data on application forms. Only South Carolina requires the collection of such data.** Findings have been shared with the National Committee on Vital and Health Statistics, the American Public Health Association, the American Association of Health Plans, the HMO Research Network, The Commonwealth Fund, and several other health professional associations.

That concludes my testimony. I would be happy to answer any questions you may have.

Mr. SOUDER. Next we will move to Dr. Ruben King-Shaw, Deputy Administrator for the Center for Medicare and Medicaid Services.

Mr. KING-SHAW. Mr. Chairman, I thank you for the opportunity to talk about something for which I have such a long-standing compassion. Such a commitment, as expressed by the secretary and the President, is quite telling at this important time in health care policy.

Let me first say, for CMS, this is a central issue to who we are and what we do, as truly the largest health insurance company in the United States, if not the world. When we embrace the concepts of eradicating disparities, it has real meaning. We spend \$1 out of every \$3 in the health care system nationally, and in many markets we spend 50 percent or more. So our activity in this area has an implication far beyond the 70 million beneficiaries that we serve directly through Medicare, Medicaid and SCHIP, but because of some other things that we do, such as survey and certification and the market force for provider reimbursement and other types of standards of care and quality, I would suggest that we have an impact across the entire health care finance and delivery system.

So we approach these issues of health disparity with a heartfelt understanding that these issues are not minor, these people are not minor, and our efforts must not be minor. So we do not conceive of this as a minority health initiative per se. We perceive of this as efforts to eliminate disparities among ethnic communities. There are issues of fairness and integrity and equality and I would submit part of the American promise that we make to all Americans and those that come to this country. So the strategies that we have pursued at CMS tend to fall into a few areas that are logical and natural.

First, we have embraced evidence-based medicine and encourage it in every way. Using clinical practice guidelines and standing orders and performance-based measures is one of the ways we continue to move forward on these important issues. We also focus our efforts on access and delivery. We do have a very ambitious research agenda. It is highlighted in the testimony. We can talk about what those initiatives are, but to a very real extent the difference we make is in adjusting the delivery system itself to be more appropriate in delivering health care to people of ethnic populations who are underserved in the medical community or suffering from adverse outcomes or by redirecting our resources to improve access to the existing programs in ways that are successful.

We also are committed to endemic organizational change at CMS, so we have a program executive who is full-time dedicated to these efforts, Kevin Nash, who is with me here today.

We have open-door policy forums that allow people from across the country who care about the issues of diversity and disparity to be part of our discussion, priority setting and decisionmaking.

We have an Equality Council which sees the addressing of these disparities as part of its core function.

It is a quality issue as well. Daily decisionmaking must reflect these priorities as we do our job in all of the ways in which we do it.

There are several actions that I can highlight. In the interest of time, I will refer to the testimony.

There are some things which I think are important to note. We do have strong existing partnerships with members of the communities we serve that can enhance our ability through research and delivery and other initiatives to make a difference. These include the four historically black colleges of medicine: Howard, Meharry, Morehouse and Drew.

We also include in our efforts ways to have stronger relationships with colleges of pharmacy, such as Bayamon, Xavier, Hampton and also Southern.

We also do a number of things called the Hispanic Agenda for Action where we partner with leading Hispanic organizations, both clinical and communities, as we do with Asian American, Pacific Islanders and American Indian populations.

But among the most successful initiatives we have established has been the notion of embracing demonstration projects to truly improve the outcome of care for the people we serve. These have included cancer prevention and treatment demonstrations as authorized by BIPA, a number of clinically and linguistically appropriate initiatives, as well as disease management and case management initiatives that are specifically designed to improve outcomes in ethnic populations such as HIV, cancer and end stage renal analysis.

In summary, CMS will continue to do its best efforts in this area, whether we are talking about demonstration, research, intervention strategies, quality improvement organizations who are dedicated in developing best practices to improve the health outcomes of all the people we serve, including ethnic populations and racial groups, that we will continue to do this as a part of our mandate and our mission for the centers of Medicaid and Medicare services.

I look forward to having more discussion in the question and answer session on this topic.

[The prepared statement of Mr. King-Shaw follows:]



Testimony
Before the Subcommittee on Criminal Justice, Drug
Policy, and Human Resources
Committee on Government Reform
United States House of Representatives

**CMS's Role in Eliminating
Racial and Ethnic Health
Disparities**

Statement of

Ruben King-Shaw, Jr.

*Deputy Administrator and Chief Operating Officer
Centers for Medicare and Medicaid Services
U.S. Department of Health and Human Services*

For Release on Delivery
Expected at Noon
on Tuesday, May 21, 2002

Chairman Souder, Congressman Cummings, distinguished Subcommittee members, thank
you for inviting me to discuss racial and ethnic disparities in health care, and specifically,

the findings of the Institute of Medicine's recent report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. According to the IOM's report, racial and ethnic populations tend to receive lower-quality health care than whites, even when age, income, insurance status, and severity of health conditions are comparable. Sadly, this is not a new phenomenon. Both general literature and CMS research data reveal that a consistent gap in health care exists for racial and ethnic populations. In addition, research finds that racial and ethnic populations generally feel that they are treated with disrespect when obtaining health care. The Secretary, Administrator Scully, and I find racial and ethnic health disparities to be unacceptable, as do many of our fellow Americans, and we are committed to working to develop strategies within Medicare, Medicaid, and SCHIP programs to reduce such disparities in health care. Today, I would like to take a few minutes to discuss our Agency's efforts to provide better, and more equitable health care for racial and ethnic populations.

HEALTHY PEOPLE 2010 AND CMS' EFFORTS

Secretary Tommy Thompson has designated two main goals for his Healthy People 2010 Initiative, which sets forth his national health objectives and is designed to identify the most significant preventable threats to health and to establish national goals to reduce these threats. These goals are:

- *Goal 1: Increase Quality and Years of Healthy Life*The first goal of Healthy People 2010 is to help individuals of all ages increase life expectancy and improve their quality of life.

- *Goal 2: Eliminate Health Disparities* The second goal of Healthy People 2010 is to eliminate health disparities among different segments of the population.

Administrator Scully and I are committed to the Secretary's goals of through better prevention, detection, treatment, and by expanding our education efforts. Over the last year, we have taken several steps to address racial and ethnic health disparities, and have implemented a number of projects to reach out to the racial and ethnic communities.

CMS' APPROACH AND ACTIVITIES RELATED TO THE HEALTH OF RACIAL AND ETHNIC POPULATIONS

CMS' racial and ethnic health activities focus on addressing challenges in accessing needed health services and information and in providing opportunities to respond more effectively to the needs of families from racially, ethnically, and culturally and linguistically diverse groups. As CMS administers the Medicare, Medicaid, and State Children's Health Insurance programs, the Agency is committed to serving all our beneficiaries regardless of race and ethnicity. The cornerstone of our approach is twofold: to increase the visibility and importance of this issue within the Agency and to develop forums for discussion and change.

We work on two levels to reduce disparities. First, we employ a broad agency strategy that promotes the use of evidence-based medicine. Evidence-based activities, such as the use of clinical practice guidelines and the reporting of performance measures drive toward care that is similar across population subgroups. Disparities are reduced by the application of these evidence-based practices, while care of the overall population is improved. Second, we work to reduce the disparities caused by differing access to health care services. Examples of both of these strategies are provided throughout this testimony.

We have worked tirelessly to ensure that activities related to race and ethnicity within the day-to-day operations and mission of each of our centers and offices are institutionalized.

This includes ensuring equality of access to Federal programs in racial and ethnic institutions of higher learning, along with enhancing workforce diversity, data, research, access to Department services, procurement, and cross-cutting collaboration within HHS.

Additionally, in an effort to manage, oversee, and coordinate racial and ethnic health disparity initiatives, we have established a Program Executive position within the Agency

who is responsible for addressing these issues. This position reports directly to me. In addition to increasing the issue's visibility through institutional change, we also have developed a number of race- and ethnicity-related discussion forums at CMS. For example, we established a Diversity Open Door Forum and directed a Quality Council to focus on quality and clinical issues that impact people of color. In addition, we have taken actions to address racial and ethnic health disparities that fall into four major categories: outreach and education; quality improvement projects; research and demonstrations.

OUTREACH AND EDUCATION

According to some of the IOM committee's recommendations, reducing disparities in health care for racial and ethnic populations requires increased patient education, more health care providers from racial and ethnic populations, and increased focus and utilization of community-based health care providers and non-medical personnel. CMS is engaged in many outreach and education activities that support the IOM's recommendations for meeting the needs of our racial and ethnic beneficiaries. Other outreach and education activities include:

REACH Campaign

Our 10 regional offices across the country are involved in a number of outreach activities targeted to underserved Medicare populations. These groups typically face barriers to information because of language, location, culture, literacy as well as disability. For example, our Atlanta regional office tours low-income, rural counties with substantial racial and ethnic populations. We also conduct 7- to 10-day media tours that are targeted toward the 70 counties in the southeastern United States in which the African-American population is greater than 50% to promote our programs. The Dallas regional office operates a special populations project, in cooperation with the National Medical Association and the Office of Minority Health to educate providers on immunization disparities among the African American community.

HORIZONS Project

We are also working through our Horizons Project to improve health education communications to African-American, Hispanic-American, Asian-American/Pacific Islander, and American-Indian and Alaska Native Medicare beneficiaries. We want to reach out to individuals in these populations who we know experience the greatest linguistics and cultural barriers to accessing health-related information. We are taking what we learn and are adapting our program publications as well as video and audio materials so that they are culturally and linguistically appropriate. One significant purpose of this initiative is to develop and share communications guidelines and materials broadly to assist public and private programs communicate effectively with underserved populations. We plan to test the new materials and develop a guide for employees so all out communications and materials are appropriate and effective.

Translated Materials

We also have a website for Medicare information, www.medicare.gov. This award-winning website contains a wealth of program, health, and quality information for beneficiaries and their families. Now, Medicare Compare, Nursing Home Compare, Medigap Compare, and ESRD Compare are available in Spanish. In addition, we have translated our Medicare printed publications, such as the annual *Medicare and You* booklet, into Spanish. We have also made a variety of program information available in Chinese.

Asian American and Pacific Islanders (AAPI) Initiative

We have developed a Hepatitis B Outreach campaign targeting the Chinese and Vietnamese populations in Boston's Chinatown. In addition, we have created a webpage at www.medicare.gov, which offers information to Chinese and have conducted a mammography awareness radio broadcast campaign in 6 major cities across the U.S. In addition, we currently have a workplan to increase this population's participation in preventive health activities, such as mammography outreach, cancer screening and prevention, Hepatitis B immunization, cervical cancer screening, and preventing the transmission of HIV from mother to child. The plan also includes increasing cultural competency in health care providers, and strengthening partnerships with AAPI community organizations.

Historically Black Colleges and Universities (HBCU)

Under this initiative, we developed a health care outreach initiative between HBCUs and Medicaid agencies. Students and personnel from three HBCUs were trained by State Medicaid Agency staff on the eligibility application intake process for the SCHIP and dual-eligibles programs. The HBCUs distributed CMS publications about the Medicare program among African-American populations in rural areas of Mississippi and South Carolina, with special emphasis each month on a particular Medicare covered benefit (breast cancer, colorectal cancer, etc.). In addition, our Atlanta Regional Office (RO) also developed an initiative called "3E" to strengthen operational ties between HBCUs and CMS. The goals of the program are to promote a working relationship with HBCUs, to enhance and educate our managers on HBCUs, and to increase the participation of the Atlanta University Consortium (AUC) in the 3E program. We also designed a HBCU Health Services Research Grants Program to sponsor limited research projects examining health services issues of significance to African-Americans. Finally, we have developed workshops for data users and grant writers to provide researchers and faculty from HBCUs technical assistance on using CMS data and writing competitive grant applications.

Hispanic Agenda for Action

We also have developed an action plan to meet the goals of the President's Executive Order on Educational Excellence for Hispanic Americans. This includes aggressive strategies for improving Hispanic participation in Federal programs in 2002 and beyond. We want to increase Hispanic representation in our workforce; strengthen and support our Hispanic health services research grants program; and strengthen our bilingual capacity. We already have awarded grants to researchers to conduct research on access, utilization, quality of services, and activities related to health screening, prevention, and education of Hispanic American Medicare and Medicaid beneficiaries.

Similar to our work with HBCU, we have developed workshops for data users and grant writers providing technical assistance on using our data and writing competitive grant applications.

We are also working closely with the academic medical community to promote culturally appropriate training in medical schools and continuing education programs to improve providers' knowledge of these issues. Historically non-white colleges and universities are key to our effort. Our goal is to increase providers' interest in serving racial and ethnic groups.

QUALITY IMPROVEMENT PROJECTS

As I mentioned in my introduction, the IOM report found that racial and ethnic groups tend to receive lower-quality health care than whites. Moreover, research has shown that the disparities in the quality of health care delivered to racial and ethnic patients are often associated with poor health outcomes. For example, a number of studies have found that patients from racial and ethnic groups are less likely to be given appropriate cardiac medications or to undergo bypass surgery. Patients from racial and ethnic groups also are less likely to receive the most sophisticated treatments for HIV infection, which could forestall the onset of AIDS. Additionally, racial and ethnic groups are more likely to receive certain less-desirable procedures, such as lower limb amputations for diabetes and other conditions. This disparity in treatment is clearly unacceptable. We are actively involved in efforts to improve health care quality for all our beneficiaries, and have

implemented a variety of quality-related initiatives targeted specifically to racial and ethnic groups and other underserved populations.

One example of our success is the End-Stage Renal Disease (ESRD) Program. Prior to the enactment of Medicare reimbursement for dialysis, African Americans were a small portion of prevalent dialysis patients. Currently, there is little difference between African-American and Caucasian ESRD patients in their ability to obtain dialysis. The ESRD Clinical performance Measures Project was our first nationwide study to improve the care of ESRD patients. Our goal was to provide the appropriate dose of hemodialysis, since numerous studies have demonstrated a relationship between low dialysis and high patient mortality. Studies had shown that there was a 60% greater likelihood of an African-American patient receiving a lower dialysis dose than a Caucasian patient. Our strategy for using clinical practice guidelines has shown improvements in the dose of dialysis for all patients at risk. Importantly, blacks realized the largest gains in the dose of dialysis, thereby resulting in a substantial narrowing of the difference between African Americans and Caucasians in achieving adequate dialysis dosage.

Reducing Health Care Disparities through the Quality Improvement Organizations

In coordination through our Quality Improvement Organization (QIOs, formerly Peer Review Organizations), we are raising the quality of care for beneficiaries who are members of disadvantaged groups to the level of all other beneficiaries living in a particular State. Under this initiative for example, QIOs are playing a leading role in improving the delivery of immunizations and mammography, and improving the quality of diabetes care.

The National Quality Assessment and Performance Improvement Project for Medicare+Choice

Each year, all Medicare + Choice organizations (M+CO) participate in quality improvement projects. This coming year we have asked plans to participate in one of two projects. One project is designed to measure plans' successes in reducing clinical health

disparities and the other is targeted toward improving plans' efforts to provide linguistically appropriate care services.

Cancer Prevention and Treatment Demonstration

In addition, we are conducting a cancer prevention and treatment demonstration project for racial and ethnic populations in the Medicare program, as mandated by The Benefits Improvement and Protection Act of 2000 (BIPA). Under this initiative, we are identifying and testing cost-effective models of intervention that have a high probability of positively impacting one or more health outcomes – including health status, functional status, quality of life, health-related behavior, consumer satisfaction, health care costs, and appropriate utilization of covered services – among targeted racial and ethnic populations. The first phase of the project involves producing a best practices report on primary and secondary prevention interventions among the targeted racial and ethnic populations. The second phase requires that our contracted partner, Brandeis University, design and implement behavioral risk factor reduction and health promotion demonstrations for each of the targeted populations. At the conclusion of the demonstrations, we will deliver a report to Congress on the cost-effectiveness of the projects, as well as the quality of preventive services provided and beneficiary satisfaction. This research will help inform future project and improve overall quality of care for Medicare beneficiaries.

RESEARCH AND DEMONSTRATIONS

The IOM report called for more research in identifying sources of health disparities, as well as determining future intervention strategies. At CMS, we have already developed a research agenda focused on the elimination of racial and ethnic health disparities in delivery of health care. For example, we are supporting several expert research efforts to address health disparities among Medicaid, SCHIP, and Medicare beneficiaries. The goal is to develop recommendations and strategies for shaping our future research agenda as well as developing an overall strategic plan to eliminate health disparities in racial and ethnic populations in all our programs. The expert consultants will focus their initial research on American Indians, Asians and Pacific Islanders, Hispanics, and African Americans. They will perform a thorough review of existing literature and data regarding health and health disparities. Consistent with the Healthy People 2010 Initiative, they will also examine the impact of variables such as income, insurance, access, cost, and culture on health disparities in the following areas: infant mortality; cancer screening; cardiovascular disease; diabetes; HIV/AIDS rates; and child and adult immunization levels.

We also are conducting a two-phase project to examine American Indian/Alaska Native eligibility and enrollment barriers in Medicaid, SCHIP, and Medicare. We plan to analyze data from CMS, IHS, and Census databases to estimate enrollment in the programs as well as identify gaps between eligibility and enrollment in Medicare, Medicaid, and SCHIP. We also plan to perform case studies and set up focus groups to examine barriers to enrollment as well as develop effective strategies for increasing enrollment in these programs.

Additionally, we are currently undertaking a series of disease management demonstration projects within the Medicare+Choice program to explore a variety of ways to improve beneficiary care in the traditional Medicare plan. These projects have particular significance to racial and ethnic populations for two reasons. First, as research conducted by the Blue Cross and Blue Shield Association and released last month reveals, members of racial and ethnic populations with low incomes who do not have supplemental Medigap or employer-sponsored coverage are more likely to enroll in Medicare+Choice. Additionally, the IOM report shows that racial and ethnic groups are less likely to enjoy a consistent relationship with a care provider, and numerous studies report that non-whites are more likely to suffer from chronic conditions, such as diabetes and asthma. For example, research shows that members of racial and ethnic groups have a higher prevalence of diabetes than whites, while asthma has a disproportionate higher rate among non-white children. Several studies have suggested that case management and disease management programs, such as those provided by Medicare+Choice plans, can improve medical treatment plans, reduce avoidable hospital admissions, and promote other desirable outcomes. Coordination of care has the potential to improve the health status and quality of life for beneficiaries with chronic illnesses. We believe disease management is a critical element for preventing the worsening of chronic health conditions, and thus these demonstrations provide beneficiaries, particularly non-white beneficiaries, with greater choices, enhance the quality of their care, and offer better value for the dollars spent on health care.

CONCLUSION

We recognize that the gross disparities between racial and ethnic groups access to and quality of health care is unacceptable. Over the last year, we have taken several steps to address racial and ethnic health disparities. We have many projects underway and we are committed to reaching out to racial and ethnic communities. These projects will help increase access to information and services, and ultimately, reduce disparities in health outcomes. However, we realize that we have more to do and are committed to working with our partners in the Department and Congress to achieve our shared goals.

Thank you for inviting me to speak on this issue today. As many of you know, eliminating racial and ethnic disparities in health care is both a professional and personal passion of mine, and I welcome any questions you may have for me.

Mr. SOUDER. Last we will hear from Dr. Karen Clancy, Associate Director, Agency for Healthcare Research and Quality.

Dr. CLANCY. Good afternoon. I am Carolyn Clancy, the Acting Director of the Agency for Healthcare Research and Quality, or AHRQ. I am very happy to be here today to discuss the relationship of the research we support to the issues raised by the Institute of Medicine report on unequal treatment. Our research provided an important underpinning for the report and AHRQ is beginning to respond to the issues raised by that report. I would like to leave you with a sense of that.

I would like to make two observations. First, to make clear that we are a research agency but the work that we sponsor actually complements the work supported by NIH. Where NIH's biomedical agenda focuses on what science is needed to address pure prevention and treatment of disease, what treatments can work, our research focuses on effectiveness or what does work for individual patients in typical or real-world practice settings.

In addition, our research, besides focusing on the content of clinical care and the persons with those illnesses—because, after all, many persons come with two or three different diagnoses—we focus on how that care is organized, the impact of health insurance, what sorts of settings people get their care in, and so forth.

The second observation is the issue of poor quality care is most marked and severe for members of racial and ethnic minority populations, but it is also a problem for all of us. We sponsored a study that was cited in the report and was published 2 years ago in the *New England Journal of Medicine* which asked: What proportion of Medicare beneficiaries who have had a heart attack are receiving an evidence-based, life-saving treatment, also known as clot busters, or thrombolysis? What the study found was that 59 percent of white men, 56 percent of white women, 50 percent of black men and 44 percent of black women who met the criteria for these drugs were receiving them.

So it seems to us that there are two important messages. First and foremost, this study confirms the results of far too many studies showing that African Americans are significantly less likely to receive evidence-based lifesaving treatments, and it underscores Dr. King-Shaw's points about the importance of evidence-based medicine.

But the second take-home message is that 59 percent of eligible patients, which is the best that we did, is not so great and that there is room for quality improvement for all of us. We therefore believe and it is a point which has been made by Dr. Blend and others, that reducing and eliminating disparities in health care is a very critical part of overall strategies to improve quality.

As I noted, many of our studies contributed to the IOM report *Unequal Treatment*. One in particular created a lot of attention and as a practicing physician makes me embarrassed to tell you about. This was a study that showed that physicians are part of the problem, not part of the solution. Well-trained actors were trained to portray patients with chest pain. They used literally the same wording and language, all of the information provided to the doctors and interacted with the videotapes of the actors, told them they had the same income, occupation, and so forth. What the

study found was that the physicians were significantly less likely to recommend evidence-based treatment for older African American women, and this study prompted a great deal of discussion and concern.

I would like to tell you a little bit about our efforts to reduce and eliminate disparities. We have pretty much informed our researchers that we have heard enough descriptive information and, as IOM study demonstrates, the time to simply describe the problem any more fully has probably passed. Now we need to focus on understanding why these disparities in health care occur and what strategies can be used to reduce and eliminate them.

The centerpiece of our research program is called EXCEED, Excellence Centers to Eliminate Ethnic and Racial Disparities in Health Care. This is a 5-year grant that began in 2000, and it is a collaborative effort with NIH, specifically Dr. Ruffin, and HRSA, as well as some other local foundations. Each of these focuses on four to seven studies organized around a particular problem and organized around the six priority areas of reducing racial and ethnic disparities in health initiative.

In addition, we have supported nearly 200 grants and contracts just since 1999 alone.

In response to the Minority Health and Health Disparity Act of 2000, we have also begun this past year to develop a very specific focus on community-based participatory research. Too often, as many know, minority communities and other communities believe that research is something that is done "to us." The purpose of this focus on participatory research is to shift that framework so, from the community's perspective the understanding is that there will be nothing "about us without us." We look forward to reporting on our future plans to you soon.

We are also supporting some very important training initiatives to make sure the perspectives of the research community accurately reflect the diversity of the current population.

Importantly, a unique function of AHRQ is to develop the tools to measure and monitor our progress, to help us make sure that Mr. Cummings' crystal ball is as clear as possible. We support the development of quality measurement tools. In fact, the Minority Health and Health Disparity Act has asked us to report to Congress on the state of the science for quality measurement for disparity populations; and we will be submitting that to Congress this year.

Very importantly, our reauthorization in 1999 directs the agency to produce two annual unprecedented reports starting in fiscal year 2003. One will report on the overall state of the quality of health care and the other is called the National Health Care Disparities Report. This will detail prevailing disparities in health care delivery as it relates to racial factors and socioeconomic factors in minority populations.

The two reports are closely linked. The disparities report will report on quality measures presented by race, ethnicity and socioeconomic status. It will also report on consumer and patient assessments of health care quality and quality measures for priority areas.

Mr. Chairman, we are very proud of our tradition of supporting research to identify and address racial and ethnic inequities and the outcomes of health care services in this Nation. The findings of the IOM report are very sobering, but we believe there is a very important opportunity to establish elimination of disparities as a priority. Health care is a core component of efforts to improve quality of care for everyone, and our current initiatives are designed to reinforce and strengthen that opportunity.

Thank you.

Mr. SOUDER. Thank you.

[The prepared statement of Dr. Clancy follows:]

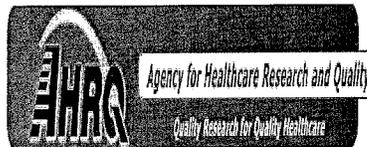


Testimony

Before the Subcommittee on Criminal Justice,
Drug Policy, and Human Resources,
Committee on Government Reform
United States House of Representatives

**AHRQ's Role in Eliminating Racial and
Ethnic Disparities in Health**

*Statement of
Carolyn Clancy, M.D.
Acting Director,
Agency for Healthcare Research and Quality
Department of Health and Human Services*



For Release on Delivery
Expected at Noon
on Tuesday, May 21, 2002

Mr. Chairman, I appreciate this opportunity to discuss the relationship of the research of the Agency for Healthcare Research Quality (AHRQ) to the issues raised by the Institute of Medicine (IOM) report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. AHRQ research provided an important underpinning for the IOM report and the agency worked closely with the IOM committee throughout the development of their report. Most importantly, I want to discuss how AHRQ's agenda, through its research and other activities, is increasingly focused on identification of effective strategies for eliminating these disparities and monitoring our progress toward that goal.

Two Observations

Mr. Chairman, before turning to the IOM report, I would like to offer two observations. First, I would like to put in context how the research of the National Institute of Health and AHRQ complement each other. The biomedical research of NIH focuses on the processes of disease, the functioning of body systems, the uniqueness of our genetic make-up, and the interaction of all of these factors with our environment. NIH identifies what can work to improve patient health through research on the "efficacy" of health care services, determining which services might work under ideal conditions. As a result, NIH plays a critical role in expanding our options for preventing, diagnosing, treating, and even curing disease.

AHRQ complements NIH by focusing on the "effectiveness" of clinical services: developing the scientific evidence regarding which patients benefit most from specific health care services under ordinary, day-to-day conditions. The effectiveness of

promising new interventions can be undermined by a host of other factors: other medical conditions or diseases of the patient; interaction with other drugs; the difficulty or unpleasantness of complying with the treatment; or the impact of economic or insurance coverage issues, to name just a few. In addition, providers may not be certain that the findings of a clinical trial apply to their patients and there is often little information that permits a provider to compare the comparative effectiveness and cost-effectiveness of different services. AHRQ research is intended to address these types of issues.

But our mission has another important dimension: AHRQ evaluates the effectiveness and efficiency of how we organize, manage, and finance health care services. Our research has demonstrated that efforts to improve the quality and safety of patient care require that we link scientific evidence on services that work with evidence on how best to organize and manage the settings where patients receive their care. We also focus on the circumstances under which caregivers deliver the highest quality care and the types of support and incentives necessary for them to do that. For example, we have sponsored studies demonstrating that for surgical procedures performed for Medicare beneficiaries, there is a clear relationship between volume and quality.

Second, it is important to recognize that the issue of poor quality care is not merely an issue for special populations, such as racial and ethnic groups, the economically disadvantaged, or the disabled. The reality is that this problem affects all of us. An AHRQ study published in the *New England Journal of Medicine* regarding clot-busting drugs that found that for Medicare beneficiaries, only 59 percent of white

men, 56 percent of white women, 50 percent of black men, and 44 percent of black women, who met the clinical criteria for these drugs, received them. These results indicate that while significant disparities associated with race and ethnicity exist, the group with the best results still has ample room for improvement. In short, disparities associated with race and ethnicity are a critical component of efforts to improve quality of care overall.

We know that some disparities in treatment will take place in the many areas of medical care for which there is no definitive evidence regarding the right treatment. However, in areas like clot-busting drugs, where science can tell us what works, we need to redouble our efforts to ensure that all Americans receive quality health care.

IOM Report on Disparities in Health Care

Mr. Chairman, AHRQ has supported research over the past decade that has documented the extensiveness of racial and ethnic disparities and identified some of the causal factors that need to be addressed. In fact, many of the studies cited in the report are the direct result of AHRQ's research investments. For example, AHRQ research found that:

- AHRQ state-of-the-art assessment of patients' experiences with care demonstrate that minorities consistently rate all aspects of their health care more negatively than whites.

- Recently reported data from the Medical Expenditure Panel Survey (MEPS) found that slightly more than half of Americans age 18 and older (53.8 percent) always received urgent medical care as soon as they wanted it in calendar year 2000. While there was very little difference between blacks and whites aged 18 to 64 in their reports of timeliness of receiving urgent care (51.5 percent and 52.9 percent respectively), significantly fewer Hispanics (41.2 percent) reported always receiving urgent care when they wanted it.
- Data from AHRQ's Healthcare Cost and Utilization Project (HCUP) demonstrated that Hispanics were significantly less likely to undergo numerous major therapeutic procedures than whites.

As a practicing physician, I am sorry to report that an important AHRQ study demonstrated that physicians can contribute to differences in access to care for blacks and women. The researchers used well-trained patient actors—two black men, two black women, two white men, and two white women—who described their chest pain using the same scripts, reporting identical clinical symptoms, and reporting the same insurance and professions. Yet even with patients in such identical circumstances, blacks and women had relative odds for being referred to cardiac catheterization, the gold standard for diagnosing coronary artery disease, that were 60% of the odds for whites and men. Black women fared the worst, with relative odds that were 40%.

Although AHRQ-supported research has told us a great deal about the existence and extent of disparities in health care, there is much we don't know. We don't know:

- All of the reasons why and how disparities occur;
- What proportion of observed disparities in health are amenable to improvements in health care;
- What local circumstances ameliorate or increase disparities (community characteristics),
- How and when to collect relevant data respectfully; and
- How to link evidence of a problem to possible solutions.

AHRQ Efforts to Reduce and Eliminate Health Care Disparities

Mr. Chairman, AHRQ has recognized for several years that the time for descriptive studies of disparities is long gone. The scope of the problem is quite clear. The research that is needed today must provide evidence on effective strategies to reduce, and ultimately eliminate, disparities in care that are unrelated to the clinical condition of the patient or patient preference.

This shift in our research direction began several years ago and was reinforced by our reauthorization in 1999 and the AHRQ-related provisions of The Minority Health and Health Disparities Act of 2000. In fact, the IOM report cites AHRQ's research and other initiatives as important efforts to develop a more systematic focus on solutions to address the causes of disparities and to provide information needed to measure and track improvement. These efforts will be the focus of the remainder of my testimony.

Developing and Evaluating Potential Solutions

Even as the Minority Health and Health Disparity legislation was moving toward passage, AHRQ was already soliciting applications for a major research effort to move in this direction. Known as *EXCEED*, (*Excellence Centers to Eliminate Ethnic and racial Disparities in Healthcare*), this project awarded 5-year grants in FY 2000 as part of a collaborative effort with the National Institutes of Health, the Health Resources and Services Administration, and a number of national and local foundations. The Centers analyze reasons for disparities and identify and evaluate the effectiveness of strategies for reducing and eliminating them.

Each of the nine Centers focuses on four to seven studies organized around a central theme. For example:

- Diabetes care, cancer screening, and other preventive services for elderly American Indians/Alaska Natives.

- Health disparities in cancer, hypertension, and HIV disease among African American adults, particularly those living in rural areas.
- Why effective care for managing premature birth, breast cancer, stroke, and hypertension is underused in ethnically diverse Harlem communities.
- Access and quality of care for chronically ill African-American adults and low-income children who primarily receive care from community providers in inner-city and rural areas.

Including EXCEED, AHRQ has supported nearly 200 grants and contracts in recent years with relevance to our health disparities agenda since 1999. A few examples include:

- Development of a culturally sensitive, interactive computer program to enhance diabetes education with inner-city African Americans and Latinos.
- Creation of a two-part training program for primary care providers uses a customized screening and charting instrument for use in adolescent preventive services.

- A nurse-mediated model is being designed to improve the delivery of clinical preventive services in primary care clinics serving low-income, largely Medicaid-eligible populations.

AHRQ is also using its network of 19 Primary Care Practice-Based Research Networks to develop strategies for improving the primary care services delivered to ethnically and socio-economically diverse populations. For example:

- The Southeast Regional Clinicians' Network, based at Morehouse School of Medicine in Atlanta, links 142 federally funded community health centers in 8 States.
- The Mount Sinai Primary Care Practice-Based Research Network links academic centers with community health centers in Harlem.

I should also note that AHRQ's 1999 reauthorization legislation authorized the establishment of the agency's Office for Priority Populations Research (OPPR). The goal of OPPR is to improve the coordination, support, management, and conduct of health services research on the priority populations enumerated in our statute. They include groups that face disparities in access and use, including minority and low-income groups, elderly, children, women, those with special health care needs, including end-of-life care, and those living in rural or inner-city areas.

Community-based Research

Mr. Chairman, we have also begun to change the way we design, conduct, and disseminate our research. For racial, ethnic, and cultural minorities, there has long been concern that research is "something done to us." EXCEED was the beginning of our effort to change both the perception and the reality of that objection. EXCEED encouraged the formation of new research relationships as well as building on existing partnerships between researchers, professional organizations, and community-based organizations instrumental in helping to influence change in local communities. The Centers are involved in participatory research efforts in which community members are involved in all stages and aspects of the studies. Several EXCEED projects are being conducted in collaboration with community health centers and other health care organizations serving ethnically diverse populations. AHRQ expects that these participatory research partnerships will help lead to more effective implementation of research findings that address the social, cultural, and economic conditions of the community.

The Health Disparities legislation went a step further by authorizing AHRQ to draw upon community-based participatory research strategies to reduce disparities. In collaboration with the Kellogg Foundation, the Office of Minority Health, and the National Institutes of Health, AHRQ hosted a two-day expert meeting last November to draw upon the expertise of those with experience in conducting community-based research, learn from community-based groups, and develop an action plan.

Building Minority Research Infrastructure

The third element in reducing disparities is to ensure that research accurately reflects the diverse perspectives of an increasingly diverse population in the United States. To accomplish this goal, AHRQ has sought to facilitate the development of greater capacity for health services research focused on reducing racial and ethnic inequities in health care. Once again, this aim was incorporated into EXCEED and several projects link new researchers with more experienced investigators through both formal and informal mentoring and career development opportunities.

Developing Tools to Measure and Monitor our Progress

Quality Measurement

As the lead agency of the Department for quality, AHRQ has played a key role in the development and validation of measures to assess the quality of health care provided to patients. The Health Disparity legislation directed the agency to draw upon its expertise in this area to develop a report describing the state-of-the-art of quality measurement for minority and other health disparity populations that will identify critical unmet needs, the current activities of the Department to address those needs, and a description of related activities in the private sector. AHRQ is working with our colleagues in the Department to prepare this report, which will be submitted to the Congress next year.

National Report on Healthcare Disparities

AHRQ's reauthorization legislation directed the Agency to produce two landmark annual reports beginning in FY 2003. The *National Quality Report (NQR)* will provide a detailed picture of the state of health care quality in America. The second report, *The National Healthcare Disparities Report (NHDR)*, will detail "prevailing disparities in health care delivery as it relates to racial factors and socioeconomic factors in priority populations." The legislation identified as priority populations rural, inner-city, low income groups, minority groups, women, children, the elderly and individuals with special health care needs.

The two reports are closely linked. For example, the "Equity" section of quality report will be expanded in the disparities report. Also, the *NHDR* will use the framework created for the *NQR*, which is being produced first. This framework will include:

- Quality measures by race, ethnicity, and socioeconomic status
- Consumer/patient assessments of healthcare quality; and
- Quality measures for priority conditions.

AHRQ is using a similar process to produce the quality and disparities reports. To that end, AHRQ has obtained expert advice regarding content and framework of the reports, including considerable input from the Institute of Medicine, broad input from the

public, discussions with public and private stakeholders, and technical expertise and data from across the Department of Health and Human Services.

Conclusion

Mr. Chairman, AHRQ is very proud of its tradition in supporting groundbreaking research to identify racial and ethnic inequities in the delivery and outcomes of health care services in this Nation. The Agency is moving forward with important initiatives that will help us understand why these gaps exist, provide the evidence-based information we need to eliminate them, and an annual report which will provide the nation a clear roadmap of our progress. The findings of "Unequal Treatment" are sobering but we believe there is an important opportunity to establish elimination of disparities in health care as a core component of efforts to improve quality of care for everyone. AHRQ's current initiatives are designed to reinforce and strengthen that opportunity.

Thank you very much for giving me the opportunity to highlight AHRQ's efforts in this area, and I will be pleased to answer any questions you may have.

Mr. SOUDER. I would first like to start with a question for Dr. Stinson. First, let me double-check, do you agree that married households generally fare better than nonmarried households in health care?

Dr. STINSON. Let me answer it this way. There has certainly been some studies that have speculated that married households fare better than unmarried households. Most of the research has surrounded the health outcomes for individuals which are one parent or unmarried households; and they clearly have shown, in those types of settings, there may be increased behavioral, mental health problems and higher incidence of substance abuse. Also, unmarried women at any age have a risk of having a child of low birth weight, which has a whole list of potential health complications.

Much of the research has been done looking at one parent or unmarried households and have looked at a lot of outcomes which have been troubling. There certainly has been an inference that in two parent or married households there are some protective natures, because it may indeed create a different type of environment with certain stabilization around supervision, nurturing, et cetera, that may have some beneficial effects on health.

Mr. SOUDER. I really appreciate your carefulness in distinctions. That is my familiarity, is that it is predominantly related to children and studies related to child-bearing mothers. Do you know if you are just single, no children? Part of the assumption is, if there are two people there, there is a certain amount of commitment and responsibility and prodding each other, as my wife particularly prods me to get things checked out. Do you know much about that?

Dr. STINSON. I am clearly not an expert on those studies. I don't know the answer to your question.

Mr. SOUDER. Let me ask, because there actually has been an increase in the percent of marriage and minority individuals. The bottom line is that we know, freezing insurance and freezing income, there are still disparities. Part of the question is, in freezing this variable, what would happen? If in fact some of the improvement in relative disparities—is that improvement partly related to the marriage variable as well? Does anybody have any idea regarding that data?

Dr. CLANCY. Our studies have not specifically looked at this with regard to race and ethnicity, but there are many studies in the literature which support the contention that being unmarried is not associated with good health in men in particular. Every time it comes up at a meeting and someone asks why is that, usually the researcher steps back and says, "I am not sure I want to speculate on why that is." It clearly is a very important factor for men's health.

Mr. SOUDER. I was a staffer for Senator Coates for 10 years before I became a Congressman, and I worked with Senator Coates to try to encourage HHS to have this data in it. It is not clear how much we can actually affect that behavior pattern or what role it is of government to affect that behavior pattern, but we ought to know from a scientific standpoint whether or not marriage is one of the variables.

Let me ask another controversial question, and that is in relations to Hispanics, and this would be very difficult to find, but is part of the disparity the illegal immigrant question and even an unwillingness to respond because of fear of the researcher? How much of the disparity is in that subgroup?

Mr. KING-SHAW. Mr. Chairman, in southern Florida, clearly when you have a population that arrives in this country that is formally disconnected from the health care system in any way except the emergency room, then you have all of the problems that are generated by not having a continuous relationship with the health care system. Primary care, diagnostic treatment, education, case management, all those things that would normally be a part of a connected person to health care would not be in an immigrant population or a migrant population. They tended to have much of the same characteristics.

There is also the issue that people can arrive in this country not having achieved strong health status before they arrived. So there is no connection with the health care system going forward to keep them healthy, but it can be very difficult to become healthy when you arrive with a situation which has already put you behind the eight ball, so to speak.

That is anecdotal. Most people would agree if you are from areas that are high in the population of immigrant individuals, I am sure there is some quantifiable data that could bear that out. I just can't cite any at this particular time.

Dr. STINSON. Mr. Chairman, your question points out how difficult it is in trying to parse out all of the different factors that play a role in health disparities. Some of the literature shows in some of the newly arrived immigrants, some of the individuals from Asia, some of them actually have better rates in some of the diseases, especially in that population in cancer, than the individuals who stay here and become U.S. citizens. Over the years, that cohort ends up developing some of the disparities that we have seen, even though, when they first arrived, they did not exhibit any differences in the population in general. It makes it difficult to generalize or to assume that in every situation, every group, that disparity existed prior to immigration to this Nation.

Mr. SOUDER. I appreciate that. Often, we do not understand the complexity of it, and the research needs to make sure that we have all of the variabilities. We all know if you do not have access to a provider you are certainly going to be less healthy, or if you do not have knowledge of what is available you are going to be less healthy. But we are not doing that great with any part of the population, as has been pointed out, and so some are internal variables.

I yield to Mr. Cummings, and hopefully we can finish this panel before we leave to vote.

Mr. CUMMINGS. Dr. Clancy, I am concerned about the funding for the EXCEED program and other initiatives with regard to health disparities. Correct me if I'm wrong, it is my understanding that the President has asked that your agency budget fall from \$300 million to \$251 million next year?

Dr. CLANCY. That's correct.

Mr. CUMMINGS. And I also understand that \$192 million of the \$251 million is protected for specific projects; is that correct?

Dr. CLANCY. That's correct.

Mr. CUMMINGS. That means that \$49 million must be cut from the remaining \$108 million. Does EXCEED fall into the group of programs that collectively face that 46 percent cut?

Dr. CLANCY. Yes, it does.

Mr. CUMMINGS. How do you see that affecting EXCEED? It seems like it is getting ready to be—it apparently is going to be cut substantially?

Dr. CLANCY. The impact on the Centers for Excellence will be less than 46 percent because the core funding for some of them comes from the National Center for Minority Health and Health Disparities and a little bit from some other foundations. So the net impact overall across the nine centers I would guess would be somewhere between 25 and 30 percent cut in the outyears. The majority of funding does come from AHRQ, though.

Mr. CUMMINGS. I know you have to support the President's budget, but when you consider the fact that literally as we sit here—and I heard your testimony about how this is a problem that does affect a lot of people—but as we sit here, people are dying needlessly.

One of the things that was so painful for me to read this, because I had a relative who had an amputation, part of the report talks about if you are African American, you have a 3.6 percentage point times chance of having a lower limb amputated if you have diabetes, same stage. For the life of me, there is something wrong with this picture. And cutting the EXCEED program—and 25 percent is a substantial cut in anybody's estimation—I was just wondering how do you feel about that? People are literally dying, that is the other piece. People are dying, and they are dying early. I was just curious.

Dr. CLANCY. All of the research efforts that you have heard about from Dr. Ruffin and from myself, and the others on the panel, it is discouraging that it takes time to buildup a critical mass of researchers to actually establish relationships with communities and local change agents, who can take the findings from the work and actually ensure that they are translated into practice and institutionalized.

The timing for the cuts for these centers will be very difficult because they will be at a point where they are beginning to test and evaluate some potential strategies for reducing or eliminating disparities.

Mr. CUMMINGS. Dr. Stinson, you were talking about the various programs that you all have to inform people and what have you. If you read the report, it seems like you can get the information to the people, but then when they get in the doctor's office—and a lot is just getting them to the doctor's office. At the doctor's office, they face another hurdle. I was just wondering, how do you get to that? Are you following me?

Dr. STINSON. Yes. It is crucial that we do not blame the individual, put all of the burden on the person in that it clearly is important for all of us to understand what we need to do as far as eating right and exercising, all those things that can help us remain healthy.

But, as importantly, we have to really engage the health professionals in a different way, in a more direct way, in a way that they understand that the foundation of delivering health care that is of the highest quality is that they have to communicate effectively with whoever comes through their door. That means they have to understand that, just like anybody else, we have to be very objective, be very deliberate and very focused on how do we address the problems of the patients that come through the door.

The pledge that all health professionals make in delivering the best quality of care just does not happen naturally. You have to think about your practice, you have to think about how you can provide the best care to every patient that comes through your door.

Mr. CUMMINGS. I agree with that. We have to go to a vote, so I have to cut you off. I am just saying this as a general statement, not directed to any particular person.

I wish people in government would look at these problems with the urgency they would look at them if it was their relative, their wife or child, that was involved. Then I think people would literally go crazy trying to solve these problems.

Every human being has value, and I just think that it gets so frustrating. When I read that report, I felt like vomiting. It was so alarming to think that so many people are dying. A cut here, a cut there, it is just a few people. They are going to die, suffer, so what? Then when I think about the things that we concern ourselves with, it just seems—the unfairness continues.

I thank you all for being here.

Mr. SOUDER. I thank you as well and certainly encourage the outreach efforts. I have participated in two minority health fairs in Fort Wayne, Indiana, where they give free blood pressure and other screenings. They do them at community-based organizations or a mall where the people actually go, which is one of the really important things in the outreach. I think if we continue to all be aware of these health disparities and work at it, we can all make progress.

Mr. Waxman also had some questions for this panel, which will be submitted for the record.

We will temporarily recess, and we have a number of votes, so we will be a little while.

The hearing stands in recess.

[Recess.]

Mr. SOUDER. Call the subcommittee back to order. And as you've heard our procedure, we need to swear our witnesses in. Congresswoman Christensen does not have to be sworn in. It's a long-standing protocol but I understand it's because when we take our oath of office we already take this oath. So if Dr. Rios and Dr. Cooper could stand.

[Witnesses sworn.]

Mr. SOUDER. Let the record show that both witnesses responded in the affirmative. Now, if you can summarize your testimony and we'll submit your whole statement in the record, and I'll be a little liberal with that. I appreciate how long you had to wait and I appreciate your willingness to stay for this panel and put up with our voting patterns in the House.

With that, Congresswoman Christensen, we'll let you begin.

STATEMENTS OF HON. DONNA M. CHRISTENSEN, A DELEGATE IN CONGRESS FROM THE TERRITORY OF THE VIRGIN ISLANDS; DR. THOMAS LAVEIST, ASSOCIATE PROFESSOR, JOHNS HOPKINS SCHOOL OF PUBLIC HEALTH; DR. LISA COOPER, ASSOCIATE PROFESSOR, JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE; AND DR. ELENA RIOS, PRESIDENT, NATIONAL HISPANIC MEDICAL ASSOCIATION

Mrs. CHRISTENSEN. Thank you. Good afternoon, Chairman Souder, Ranking Member Cummings. Thank you for the opportunity to testify at what I feel is a very important hearing.

The IOM report, which is at the center of this hearing, I think speaks for itself so I am not going to use my allotted time to recount the filings and I will summarize my written testimony.

I particularly appreciate this hearing because this gives us an opportunity to have this information on an official record. As you know, we in the Congressional Black and Hispanic as well as the Asian Pacific Islander Caucuses held a hearing earlier this year on the report and the Department's response to the presence of health disparities. I am going to focus my remarks on issues surrounding the Department of Health and Human Services.

Let me begin with the issue of diversity within the Department. We recognize and appreciate the work of Deputy Secretary Claude Allen and we have a great respect for his knowledge, understanding and his compassion about the health care disparities, but we do not feel that the Department's diversity goes deep enough. We are not convinced, for example, that the Office of Minority Health and the Office of the Secretary had direct influence on decision-making and policy setting across the Department. All of the offices of minority health must have their own budget, and their functions need to be institutionalized.

Neither the Office of Minority Health or other programs critical to the elimination of disparities of health care, including the Agency for Health Care Quality and Research, which carries much of the mandate to develop policies to eliminate those disparities, have budgets that are reflective of a serious commitment.

The Center for Minority and Disparity Health Research's budget has increased but we don't see any evidence that convinces us that center has full trans-authority for all minority and disparity research dollars at NIH or that it has adequate funding to support critical research infrastructure development or improvement at our minority health professions schools.

The bottom line is that we are concerned that the Department's direction and focus has changed dramatically to one primarily of cost containment instead of one of providing the resources necessary to promote and restore good health, given that inequities exist, which if allowed to continue will threaten the very fabric of our Nation, and major investments must be made up front immediately to level the playing field or we will never control health care costs, not to mention save lives, which is really of primary importance.

Let me focus on a few issues, other issues. One of the important limitations, as you've heard, in the effort to eliminate disparities is

the lack of data. A study commissioned by the Commonwealth Fund and done by the Summit Health Institute for Research and Education found that while the collection of data by race, ethnicity and language is legal, there is no uniform data collection within the Department of Health and Human Services. It is critical that the Secretary direct the Department to collect this data and, if need be, that Congress so direct the Secretary.

One of the great barriers to appropriate health care is that of language differences between that of provider and patient. Patients are caught in between providers who are experiencing cuts that are driving them to close their offices and the need for the interpreters on the other hand. CMS must pay for those services, the services of the interpreter as well as restore the cuts and provider payments.

This leads me to work force development. Much of the gap in health care for racial, ethnic and linguistic minorities in this country would be closed if we had more providers of the same language and same background. Yet education and training programs are cut in the proposed 2003 budget by more than \$200 million. This needs to be restored, with emphasis on training providers of color.

With regard to physicians of color already in practice, the programs of the Center for Medicare and Medicaid Services, their denials, their audits and their cuts in funding are driving an already marginalized group of practitioners out of business. The managed care system just makes the situation worse. We need a study to document what is happening to these physicians and CMS should require that all managed care organizations and group insurances provide services in medically underserved and high disparity communities and include the providers of those communities who are now systematically excluded. Subsidizing malpractice premiums to the degree that these providers care for patients covered by CMS also should be considered.

Until the health care landscape is equal for all Americans all programs should be directed to place emphasis on areas where high disparities exist for the purposes of increased funding, for placement of National Health Service Corps physicians, and for community health centers, and also within the homeland security bioterrorism initiative. All areas of this country's public health infrastructure must be strong and intact or no one will be safe.

The need for and the importance of universal coverage to reverse the inequities in health care cannot be overemphasized. Every year 83,000 people die for the specific reason that they lack insurance.

Three more issues very briefly. A revolution must take place in strategies for addressing disease in our communities if we are to begin to see change. The most effective way to improve the health of our communities is by empowering the communities themselves through direct funding and technical assistance so that they can be their own agent of wellness. That is what we in the Congressional Black Caucus and Hispanic Caucus are attempting to do to the Minority HIV/AIDS Initiative, but under current departmental directives funding that used to be targeted to the community organizations within those communities of color just for this relatively small but critical program will no longer be so directed. And so we ask this committee to consider that the devastation of this tragic epi-

demic in communities of color constitutes a compelling government interest which meets the test of Adarand.

We further request your assistance in restoring language to appropriately target the funding to build the capacity of the community and faith-based organizations our communities have long trusted and responded to so that we can bring this epidemic and all of the other disparities under control.

A central issue is also the need for an effective Office of Civil Rights within the Department of Health and Human Services. In addition to a permanent director, this office also needs a significant funding increase for 2003.

I would like to cite one important case which was the subject of testimony at our hearing which needs to be addressed. It's the Sandoval case in which the U.S. Supreme Court last year held that private individuals could not sue State agencies under Title IV of the 1964 Civil Rights Act for unintentional discrimination. Given the lengths to which they went, it is felt that the decision may signal a bad omen for the future of substantive agency rules condemning disparity impact under Title VI. Reversing the Sandoval decision is a high priority in eliminating racial and ethnic disparities in health care.

Finally, the health care needs of American citizens in our territories whose Medicaid funding is capped and of the Native American peoples who suffer some of the greatest disparities in several areas must not be overlooked. This testimony just represents a few of the important concerns we have concerning the Department's policies and operations and the health care system nationwide.

I really welcome and commend the subcommittee's interest and concern about this issue that is so vital to the community, communities which make up a significant portion of the population of this country. African Americans, Native Americans and other people of color, like all Americans, have the right to good health care but have long been denied. We are working with the members of this subcommittee to ensure complete access to all Americans for all Americans to quality health care. That is the only system that this country is worthy of.

Thank you.

[The prepared statement of Mrs. Christensen follows:]

STATEMENT
OF THE HON. DONNA M. CHRISTENSEN
BEFORE THE SUBCOMMITTEE ON CRIMINAL JUSTICE,
DRUG POLICY AND HUMAN RESOURCES
HOUSE GOVERNMENT REFORM COMMITTEE

May 21, 2003

Good morning, Chairman Souder, Ranking Member Cummings and members of the subcommittee, thank you for the opportunity to testify at this hearing which is as important, in my opinion, as the one on the issue of National Security which was recently held by your the full committee.

The unequal treatment that is present in our health care delivery system is very relevant to National Security. First, it threatens our ability to have the best defense forces at home and abroad. Further, the fact that inequality in health is due in large part to racism and discrimination in the system is an indication that this likely exists throughout systems and institutions across the board in this country. This bodes ill for us as a country with an increasingly diverse population.

The recent report of the Institute of Medicine, (IOM) which is at the center of this hearing is a compilation of data which clearly shows that racism and discrimination exists in the health care system, and that there are institutions which support or at least do not mitigate them. This report on a major root cause of the poor health of minorities in this country, speaks for itself and so I will not use my allotted time to recount its findings.

The Caucuses representing African-Americans, Hispanics, and Asian Pacific Island Americans held a hearing earlier this year on the IOM report and the Department OF Health and Humans Services' response to the presence of disparities in health. My remarks today will focus on some of the issues raised by Department.

Let me begin with the issue of diversity within the HHS. We recognize, the presence of Dep. Secretary Claude Allen, and have a great deal of respect for his knowledge understanding and compassion about the issue of health disparities, but we do not feel that the commitment to diversity goes deep enough, Department-wide. In our questioning of the Director of the Office of Minority Health at our hearing we were left un-assured that this was an institutionalized process, although he tried his best to convince us that his office had direct influence on decision making and policy setting across the department.

For effective representation of issues affecting communities of color, the influence of this Office, or the offices of Minority Health within the agencies, cannot be left to the whim or good intentions of directors or Secretaries. It must be institutionalized in law and those offices within the agencies must have their own budget.

The Office of Minority Health itself has not seen its funding increase commensurate with the Department's purported emphasis on the elimination of disparities. As a matter of fact, none of the programs critical to the elimination of disparities in health care have budgets reflective of a serious commitment.

The Agency for Healthcare Quality and Research, which carries much of the mandate to develop policies to eliminate disparities, is inadequately funded to fully carry out that mandate.

In the case of The Center for Minority and Disparity Health Research, while its budget has increased, it was not doubled, as it should have been. More importantly, we see no evidence, which convinces us that this center has full trans-authority for all minority and disparity research dollars at NIH. Of critical importance, there isn't adequate funding to support research infrastructure development or improvement at minority health professions schools. The center therefore has limited access to dollars presumably put there to build capacity for research at these institutions.

In my opinion, there is a clear reason for the lack of funding support for this important initiative, and for the health programs that would best provide the prevention, training and services to support it. The Department's direction and focus has changed dramatically under the present secretary, Tommy Thompson. Its focus is now one primarily of cost containment, not of providing the resources necessary to promote good health.

Given the inequities that exist, and which if allowed to continue will threaten the very fabric of our nation, a major investment must be made up front immediately to level the playing field, or we will never control health care costs. To focus on containing costs at the expense of prevention and services, in the face of the present health care landscape, writes off the lives of the people whose health we are here discussing this morning.

Let me focus on a few other issues:

One of the important limitations in the effort to eliminate disparities is information / data. That is why the Center for Minority and Disparity Health Research role is so important, but so is data collection throughout the Department. A study commissioned by the Commonwealth fund, by SHIRE (Summit Health Institute for Research and Education), found that while it is explicitly clear that the collection of data by race, ethnicity and language is legal, within the Department of Health and Human Services there remain differing opinions on whether it is. There is therefore no uniform data collection to lend the appropriate direction to the inquiries and programs that must take place. It is critical that the Secretary direct the department to collect this data, and if need be that the Congress so direct the Secretary.

One of the great barriers to appropriate health care is that of language between provider and patient. Patients are caught in between providers who are experiencing cuts that are driving them to close their doors to Medicare patients, and sometimes entirely, and the need for interpreters. This does not need to be. CMS must pay for those services, and restore the cuts in provider payments. If these cuts are allowed to remain in place, and the

planned subsequent cuts become effective we will face a health care calamity not only in communities of color, but nationwide.

This leads me to workforce development. Much of the gap in health care for racial, ethnic and linguistic minorities in this country would be closed if we had more providers who spoke the same language and came from the same backgrounds as their patients. Yet education and training programs are cut in the proposed 2003 budget by more than \$200million. This needs to be restored, and emphasis need to be placed on training minority health care providers on all levels to meet the needs of health care in their communities.

With regard to physicians of color already in practice, the programs of Center for Medicare and Medicaid (CMS), their denials, audits, and cuts in funding, are driving an already marginalized group of practitioners out of business. And the managed care system just exacerbates this situation. We need a study to document what is happening to these physicians. Disparities caused by racism and discrimination doesn't only occur in our patients, but the provider is affected as well. CMS should require that all managed care organizations, and group insurances provide services in medically underserved and high disparity communities, which they now systematically exclude because it cuts into their profits. They should also be required to include the traditional providers who have long labored under compensated in these communities in their provider panels.

In light of the unequal burden placed on minority physicians and those who practice in these medically underserved areas, by high malpractice costs, subsidizing malpractice premiums to the degree that these providers care for patients covered by CMS, also should be considered.

Until the health care landscape is equal for all Americans, and people legally residing here, all healthcare programs should be directed to place emphasis on areas where high disparities exist, given increased funding, placed as NHSC providers, for Community Health Centers, and also within the Homeland Security, bio-terrorism initiative.

If one of this country's poor, minority or rural communities become a target, given the poor public health infrastructure that now exists in these communities, it will have an impact of dire proportions. All areas of this country's public health infrastructure must be strong and intact or everyone is at risk everywhere.

The need for and importance of universal coverage to reverse the inequities in healthcare cannot be over emphasized. Every year 83,000 deaths occur in this country that are attributed to lack of insurance. It is the 7th cause of death overall.

Three more issues:

The first is how funds to correct the inequalities in health care are to be directed. Disparities have existed for centuries and continue to increase, despite a monumental amount of dollars having been poured into heart disease, diabetes, stroke, cancer and all of the diseases which top the list of what is killing us. A change must obviously take place in the strategies for addressing disease in our communities if we are to begin to see change. The most effective way to improve the health of our communities is by empowering the communities themselves, through direct funding and technical assistance so that they can be their own agents of wellness.

This is what we are attempting to do through the minority HIV/AIDS initiative. But under the current Departmental directives, funding that used to be targeted to the community organizations within those communities of color for just this relatively small but critical program, will no longer be so directed. Which means that instead of building capacity within our communities to effect the necessary changes in lifestyle, and other factors, they will have to compete with other more experienced organizations from outside of those communities for the funding. With all due respect to those organizations, which have done a lot of good work during the past 20 years of the epidemic, if they could have been effective in our communities they would have. Today's HIV and AIDS statistics in our communities make a potent argument for change.

And so we ask this committee to consider that the devastation of this tragic epidemic in communities of color, especially the African American and Hispanic communities, largely caused by deficient health care infrastructure, the lack of culturally competent providers and the discrimination that is the subject of this report, constitutes a compelling government interest which meets the test of Adarand. Please help us restore this funding to build the capacity of the community and faith based organizations our communities have long trusted and responded to so that we can bring this epidemic, and all of the other disparities under control.

A central issue is the need for an effective office of Civil Rights within the Department of Health and Human Services.

The information in the IOM report, which reflects the experience of millions of Americans across this country, demands effective enforcement of civil rights laws with respect to access to health care as in every other area.

In addition to a permanent director with strong credentials and a proven record of commitment and expertise, this office also needs adequate funding which would mean a significant increase in 2003.

I would like to cite one important case which was a subject of testimony at our hearing, and which needs to be addressed. It is the Sandoval case.

This is a decision of the U.S. Supreme Court last year, which held that private individuals could not sue state agencies under Title VI of the 1964 Civil Rights Act for un-intentional discrimination. It represents a serious obstacle to access by people of different racial, and especially linguistic backgrounds.

At issue in Sandoval was the State of Alabama's "English-only policy", requiring all aspects of its driver's license examination process, including the English process be conducted in English. In rejecting a Mexican immigrant's claim that the state policy violated Title VI because of its "disparate" of unintentional impact on ethnic majorities.

A narrow 5-4 majority of the Supreme Court rejected Sandoval's claim and ruled that Congress did not intend a private right of action to enforce Title VI except as a remedy for intentional discrimination.

While the court did not directly confront federal agency authority to enforce Title VI compliance administratively with rules condemning practices discriminatory in the effect on protected minority groups, given the lengths to which they went to address an issue on which the federal appellate courts did not substantially disagree, it is felt that the decision may signal a bad omen for the future of substantive agency rules condemning disparate impact under Title VI.

As a result, since enforcement of regulations and statute has been recommended as an important component of a comprehensive strategy to address healthcare disparities, and in light of the fact that many racial and ethnic minorities find that language barriers pose a significant problem in their efforts to access health-care, reversing the Sandoval decision has been listed as a high priority in eliminating racial and ethnic disparities in healthcare.

Finally, the health care needs of the Native American peoples must not be overlooked. The Indian Health Service Budget is underfunded by at least \$4.4billion dollars, and there is a need to review and fix Title IV of the Indian Health Care Improvement Act, which deals with how the Medicaid System works with respect to Native American tribes.

Despite the length of this testimony it only represents the tip of the iceberg. I welcome and commend the subcommittee's interest and concern about this issue that is vital to a significant portion of the population of this country. African Americans, Native Americans and other people of color like all Americans have a right to good healthcare, and have been long denied.

The members of the Health Braintrust look forward to working with the members of the subcommittee to ensure complete access to quality health care for all Americans. That is the only system that is worthy of this great country.

Mr. SOUDER. Thank you, Congresswoman Christensen. Maybe one of the things, you can work with Mr. Cummings and if there is additional materials from your caucus' hearing that you want to see put in this official hearing record, I would be happy to work with you.

Mrs. CHRISTENSEN. I'd appreciate being able to add for the record the testimony that we gave to the Labor-HHS Subcommittee of the Committee on Appropriations as well. I have another hearing to attend that I have to testify at.

Mr. SOUDER. Thank you for taking the time and waiting for so long for us to get back.

Mrs. CHRISTENSEN. That's OK. Thank you.

Mr. SOUDER. Let's see. Dr. Cooper, we'll go with you next. You're associate professor, Johns Hopkins School of Medicine, is that correct?

Dr. COOPER. Mr. Chairman, Mr. Cummings, other honorable members of this committee, I am Lisa Cooper, M.D., Associate Professor of Medicine and of Health Policy and Management at Johns Hopkins University. I come before you today as a medical researcher, a primary care physician and a medical educator.

Over the past 10 years with my colleagues I have conducted a series of studies investigating the issue of racial and ethnic disparities in access and quality of health care services. My work has focused on the role of the Patient-physician relationship in either perpetuating or ameliorating these disparities in health care.

I am familiar with the IOM report, having contributed to the study as the author of a chapter on patient-provider communication. I would like to address three of the recommendations made in the IOM report: First, integrate cross-cultural education into the training of all current and future health professionals; second, increase the number of individuals from underrepresented minorities among health professionals; and, third, conduct further research to identify sources of ongoing racial and ethnic disparities and assess promising interventions.

First, I strongly support the recommendation that the medical community integrate cross-cultural education into the training of all current and future health professionals. The evidence to support this recommendation comes from several studies showing that ethnic minority patients experience poorer quality technical and interpersonal care from physicians. African, Asian, and Hispanic Americans as well as Native American patients in the common race discordant relationship with their physicians report less involvement and less partnership in medical decisionmaking, less respect when receiving health care, lower levels of trust in physicians and lower levels of satisfaction with care.

My colleagues and I found in a study of over 1800 managed care enrollees in Maryland, Virginia and the District of Columbia that ethnic minority patients reported their physicians were less likely to involve them in medical decisionmaking than white patients. Another recent study showed that white physicians are more likely to perceive African Americans and lower socioeconomic status patients negatively on several dimensions, including intelligence, the likelihood of engaging in high risk behavior, likelihood of adhering

to medical advice, their ratings of affiliation or liking of these patients, and several personality attributes.

While these perceptions are likely to be unconscious and unintentional, this study and several others mentioned earlier today suggests that the beliefs that physicians hold influence their interpretation of patients' symptoms, their interpersonal behavior when interacting with patients and ultimately their clinical decision-making. Therefore, it is essential that current and future health professionals at all levels receive training in intercultural communication. Legislation that mandates the inclusion of such programs into the curricula of health professional training programs supported by Federal funding such as residency and fellowship training would be particularly useful.

Second, I support the recommendation made by the IOM report that we increase the number of individuals from underrepresented racial and ethnic minorities among health professionals. The evidence to support the need for more ethnic minority health professionals comes from several studies showing that African American and Hispanic American physicians are more likely than their counterparts to provide care for underserved populations.

Additionally, we've heard before that racial and ethnic concordance between patients and providers is associated with higher levels of perceived quality of care, participation in care, and receipt of preventative care and even quality of care for some conditions, such as HIV.

In the same study I mentioned to you earlier, conducted here in Maryland, Virginia and the District of Columbia, we found that patients who were seeing a race concordant physician felt more involved in decisionmaking. The active participation by patients in medical decisionmaking with physicians is an important marker of the quality of interpersonal care because it has been related to satisfaction, longevity of the patient-provider relationship, and better health outcomes such as diabetes and hypertension control.

The goal of increasing ethnic minority health care professionals is to provide patients with more choices and access to a more diverse group of health professionals. I recommend—ask that you strongly consider supporting the continuation of policies in Federal funding to promote the training of health professionals from underrepresented minorities at all levels, including the provision of loan repayment mechanisms for physicians who provide care and conduct research to care for underserved populations.

Finally, I strongly support the recommendation that the scientific community conduct additional research to identify sources of racial and ethnic disparities and to assess promising intervention strategies. Resources from the NIH and the AHRQ have allowed medical researchers to identify and explain sources of disparity and most recently to design and evaluate interventions to eliminate these disparities. These two agencies have provided the majority of funding for the studies conducted over the past two decades in this field. More well-designed interventions with rigorous evaluation are needed. As such, the AHRQ and the NIH will need a higher level of resources to assure that the research necessary to inform health policy as well as clinical practice is done in the most effec-

tive manner and that future researchers in the field of disparities receive appropriate research training.

Finally, because access to high quality health care is an important determinant of health status, this research will likely play a pivotal role in improving the health status of the entire American public.

Thank you.

[The prepared statement of Dr. Cooper follows:]

Hearing of the Government Reform Committee's Subcommittee on Criminal Justice, Drug Policy, and Human Resources – Investigative Hearing examining racial disparities in healthcare, an overview of the Institute of Medicine (IOM) Study, “Unequal Treatment”, May 21 (Tuesday), 2002, 12:00 P.M., Rayburn House Office Building, Washington, DC.

Testimony of Lisa A. Cooper, MD, MPH, Associate Professor of Medicine and Health Policy and Management, Johns Hopkins University School of Medicine and Bloomberg School of Public Health, 2024 E. Monument Street, Suite 2-500, Baltimore, Maryland 21205. (410) 614-3659.

Mr. Chairman and other honorable members of this committee, I am Lisa A. Cooper, MD, MPH, Associate Professor of Medicine and Health Policy and Management, Johns Hopkins University School of Medicine and Bloomberg School of Public Health. I come before you as a medical researcher, primary care physician, and medical educator. Over the past ten years, with my colleagues, I have conducted a series of studies investigating the issue of racial and ethnic disparities in access and quality of healthcare services. My work has focused on patient-physician relationships and how communication between patients and physicians can either contribute to, or ameliorate racial and ethnic disparities in health care. I am familiar with the Institute of Medicine's report on this issue, having contributed to the report as the author of a chapter on patient-provider communication: the role of race and ethnicity on processes and outcomes of healthcare. I would like to address three of the recommendations made in the IOM report: 1) Integrate cross-cultural education into the training of all current and future health professionals, 2) Increase the number of individuals from underrepresented ethnic and racial

minorities among health professionals, and 3) Conduct further research to identify sources of ongoing racial and ethnic disparities and assess promising interventions.

First, the report recommends that the medical community integrate cross-cultural education into the training of all current and future health professionals. I strongly support this recommendation. The evidence to support this recommendation comes from several studies showing that ethnic minority patients experience poorer quality interpersonal care from physicians and that these communication problems may be directly linked to unconscious stereotyping behavior and biases in decision-making by physicians. African Americans, Hispanics, and other ethnic minority patients in the common race-discordant relationship with their physicians report less involvement in medical decisions, less partnership with physicians, lower levels of trust in physicians, and lower levels of satisfaction with care. My colleagues and I found in a study of over 1,800 managed care enrollees in the Maryland, Virginia, and the District of Columbia, that ethnic minority patients reported their physicians were less likely to involve them in medical decision-making than white patients. A recent national survey of over 6,700 individuals who reported having a regular physician found that African Americans, Asian Americans, and Hispanics are more likely than whites to experience difficulty communicating with their physician, to feel that they are treated with disrespect when receiving health care, and to feel they would receive better care if they were of a different race or ethnicity. Another recent study showed that white physicians are more likely to perceive African-American and lower socioeconomic status patients more negatively on several dimensions, including intelligence, likelihood of engaging in high-risk behavior, likelihood of adhering to medical advice, ratings of affiliation, and several personality attributes. These perceptions are likely to be subconscious and

unintentional; nonetheless, this study and others have suggested that physicians, like others in society, hold unconscious stereotypes that influence their interpretation of patients' symptoms, their interpersonal behavior, and ultimately their clinical decision-making. Therefore it is essential that current and future health professionals receive training in intercultural communication including a focus on affective dimensions of communication (such as nonverbal behavior), cultural awareness, and the identification and reduction of stereotyping behavior with patients. Training at all levels is important; however, legislation that mandates the inclusion of such programs in the curricula of health professional training programs supported by federal funding (i.e., residency and fellowship training) would be particularly useful.

Another recommendation made by the IOM report is that we increase the number of individuals from underrepresented racial and ethnic minorities among health professionals. I strongly support this recommendation. Evidence to support the need for more ethnic minority health professionals comes from several studies showing that African-American and Hispanic physicians, and physicians who have grown up in an underserved area, are more likely than their counterparts to provide health care for underserved populations. Additionally, racial and ethnic concordance between patients and providers is associated with higher levels of perceived involvement in medical decision-making, reported receipt of preventive care, and patient satisfaction. In the same study mentioned previously that my colleagues and I conducted in Maryland, Virginia, and the District of Columbia, primary care patients in race-concordant relationships rated their physicians as being more participatory than those in race-discordant relationships. The active participation by patients in medical decision-making with physicians is an important marker of the quality of interpersonal care because it has been related to

satisfaction, longevity of the patient-provider relationship, and better health outcomes such as blood pressure control and control of diabetes. The goal of increasing ethnic minority health care professionals is not to achieve ethnic concordance for all patients, but to provide patients with access to a diverse group of health professionals. Based on these studies, many of my colleagues and I believe the reversal of affirmative action policies and reduction of federal funding for training of health professionals will adversely affect the delivery of health care to African and Hispanic Americans. I am asking that you strongly consider supporting the continuation of policies and federal funding to promote the training of health professionals from underrepresented minorities at all levels, including, but not limited to, the provision of loan repayment mechanisms for physicians who provide care or conduct research to improve care of underserved populations.

A third recommendation made by the IOM report is that the scientific community conduct additional research to identify sources of racial and ethnic disparities and assess promising intervention strategies. I strongly support this recommendation. The majority of studies over the last two decades that have documented and identified potential sources of healthcare disparities have been conducted with funding from the National Institutes of Health (NIH) and the Agency for Healthcare Research and Quality (AHRQ). These resources from NIH and AHRQ have allowed medical researchers to identify and explain sources of disparities and most recently to design and evaluate interventions to eliminate these disparities. For some conditions (mental illness) and populations (children, certain immigrant groups and ethnic subgroups), barriers to equitable health care have not been well described, and more descriptive and explanatory research is needed. For other disease conditions (cardiovascular disease, cancer, preventive care,

asthma, diabetes, HIV) and populations (the elderly, African Americans and Latinos), research has revealed many potential targets for interventions. Well-designed interventions with rigorous evaluation are needed. These studies will need to link structural and organizational measures of healthcare quality with process of care and health outcomes data. Some important areas for further exploration should include patient-provider communication, the role of stereotyping and bias in perpetuating racial disparities, and the effectiveness of health professional intercultural communication interventions and patient education and activation interventions. Health services interventions, whether used alone or in collaboration with social and economic interventions, are likely to play a significant role in reducing racial and ethnic health disparities. The NIH will need continued financial resources, and the AHRQ will need a higher level of resources to assure that the research necessary to inform clinical practice and health care policy to eliminate disparities, is done in the most effective manner and that future researchers in the field of disparities receive appropriate research training. Because access to high quality health care is an important determinant of health status, this research will play a pivotal role in improving the health status of the entire American public. Thank you.

Enclosure: Cooper-Patrick L, Gallo JJ, Gonzales JJ, Vu HT, Powe NR, Nelson C, Ford DE. Race, gender, and partnership in the patient-physician relationship. *Journal of the American Medical Association* 1999; 282(6):583-589.

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Mr. SOUDER. Thank you very much. Dr. Cooper, who is Associate Professor—no. Dr. Rios, excuse me, I am misreading here. You're President of the National Hispanic Medical Association. Is that correct?

Dr. RIOS. Yes.

Mr. SOUDER. Are you a practicing physician or the Executive Director?

Dr. RIOS. Executive Director.

Mr. SOUDER. Thank you. Is your mic on?

Dr. RIOS. Is it on?

Chairman Souder, Congressman, HHS officials and guests, it is an honor to be here. The National Hispanic Medical Association represents licensed Hispanic physicians in the United States. The mission of NHMA is to improve the health of Hispanics.

I also work as the CEO for the Hispanic-Serving Health Professions Schools, Inc., that represents 22 medical schools and three public health schools. The mission of this organization is to develop Hispanic students and faculty and research capacity to improve Hispanic health. And I would just like to say that I think I have to agree with the Congresswoman when she said we really do need universal access and that would be—I think that would go a long way to eliminate disparities in this country if we had access to health care.

The Hispanic population right now is 14 percent of the U.S. population. By the year 2050 one out of every four Americans will be of Hispanic origin. We are the ethnic group in the country with the largest rates of uninsured. I know that the IOM report, however, discusses disparity not due to access related factors so I won't discuss insurance. But in the case of Hispanic patients we are challenged by language needs, literacy levels, lower levels of poverty and education, citizenship status, cultural beliefs and attitudes, family group decisionmaking, awareness of public health programs, or lack of awareness I should say, lack of awareness of how to even follow complex treatment regimens, how to read drug labels, where to go for further testing, x-rays or speciality care in our complicated health system.

Our health system is the best in the world, but in order to be proud of that system this report challenges all of us to develop new strategies to improve the quality of health care delivery. And we like to address just some proposed strategies for HHS to continue to decrease rates in ethnic disparities in health care. And the first area, as has been mentioned, is diversity in medicine.

The U.S. Federal Government has taken the lead to recruit and retain minority and disadvantaged health professional students since the 1960's, when it was recognized that it is a Federal Government role to develop programs that provide health care services for all vulnerable population groups in this country. Medicare for the elderly and disabled, Medicaid and community clinics for poor patients, and the National Health Service Corps and the Health Careers Opportunity Program for poor, disadvantaged or minority students so that they could become health professionals for their communities.

In the 1980's, HHS further developed these programs by addressing the—by calling—by creating the Centers of Excellence and the

Faculty Development Program for minority students at medical schools. Through its curricular efforts, the COEs impact cultural competencies of all their graduates. In addition, both of these programs have increased the number of minority faculty, although small, but they have increased the number of minority faculty that address research and curricular issues related to minority patients and communities.

The literature demonstrates many examples of studies on the outcomes of minority health professionals serving a major need in the United States, mainly that they provide health and mental health care services for minority patients of their own ethnicity and for those on Medicaid and the uninsured. And there's definitely an economic impact by having minority health professionals in this country.

HHS HRSA's Health Careers Opportunity Program and Centers of Excellence Program have proven track records of graduating two to three times more disadvantaged and minority students than the other health professions institutions in this country. However, for the second year in a row this administration has called for drastic down-sizing of these programs.

We believe strongly that the IOM is a reminder for us with the changing demographics and continued immigration of Hispanics and the needs of all minority groups to recognize the critical need for minority physicians, and currently Hispanics are only 5 percent of America's doctors and only 2 percent of America's nurses, and both of these programs should be expanded with increased funding at the level requested by Congresswoman Donna Christensen at her testimony to the appropriations hearing.

We also propose a new strategy that these programs be expanded into public-private partnerships with the medical schools, led by HRSA. The medical schools have institutionalized recruitment and retention programs. They have minority affairs offices. They have staff. But they should be required to provide more matching funds and fund-raising efforts to increase the support for these programs.

We support the request from the caucuses again to increase the support from the Federal Government, also. And why shouldn't a recruitment program be linked to academic enrichment in middle schools and grammar schools and colleges through scholarship incentive programs, for example, that could be privatized? Scholarships could be linked to the students who would be linked to programs developed at certain schools and regional consortia. Why shouldn't businesses, especially the HMOs, hospitals, pharmaceutical companies, medical suppliers and medical groups that are employers and business partners who directly benefit from their linkages with physicians be fiscal partners in the education process of future physicians?

We also recommend that there should be collection of data of the—about the alumni from these programs and link their location of practice to medically underserved areas or health professional shortage areas, as does the community clinic and the National Health Service Corps program.

Furthermore, Medicare GME funding for teaching hospitals should be linked with the policy focus to provide incentives to produce minority physicians and minority programming. There

should be loan repayment for faculty, and I think that physicians should be encouraged to sign up for the National Health Service Corps more than we are now in terms of minority physicians. President Bush's Medical Reserve Corps is another example of an effort where we could get more volunteers to work through that effort to help recruit younger students in doctor's communities.

Cross-cultural education was mentioned by my colleague. I won't go through that, just to say that it is very important because we have so few minority doctors in this country that the majority of doctors need to have cultural competency training in medical schools, and in fact the accreditation body for medical schools in this country just mandated that cross-cultural education be a requirement for medical schools so that the future generation of doctors in this country can better know how to communicate and understand and respect their patients.

We also recommend the funding for HRSA for the Cultural Competence Curriculum Demonstration Grants that were part of the Health Care Fairness Act that created the new national Center for Minority Health and Health Disparities Committee. They were never funded.

Also, the Agency for Health Care Research and Quality and the Centers for Medicare and Medicaid services should also include cultural competence training not only of the health providers, the doctors, but the health staff, the programs that they support.

Third thing is language services, and I think that it's just important to realize that there are so many people that speak other languages in this country and they do need and deserve to have access to the health care system and they do deserve to be able to communicate with their providers. I think that we understand the importance especially of Spanish speakers in this country, the increasing number of Spanish speakers and that we do know that the White House Office of Management and Budget just concluded its study on the implementation of the Limited English Proficiency Executive Order and said that the benefits seem to outweigh the costs since language services improve access to and can increase effectiveness and distribution of public health programs.

Moreover, language services will substantially improve the health and quality of life of LEP individuals and their families. We propose that HHS support demonstration programs in language services to develop the reimbursement models needed through programs that exist right now at HRSA, the community clinics at SAMHSA, the drug treatment centers, the centers for Medicare and Medicaid services through Medicare and Medicaid.

Interpreter services should be developed not only for bilingual staff and bilingual providers but for consultant interpreters. That should be developed as new auxiliary health positions with certification and training programs, and Spanish language training for providers through CME programs and for medical students should be supported significantly in targeted markets through demonstration projects.

There really is a critical need to do this now to prepare for even more Spanish speakers in the future in this country.

I also think there could be a new program for managed care partnerships in targeted States that could be used as incentives to get

Medicare programs to expand services to the Hispanic elderly. All of HHS prevention literature needs to be in different languages and media. Both English and Spanish TV, radio, Internet and print needs to be partnered by HHS to start developing targeted public health messages.

Now just a couple of systemic strategies that this report leads us to think about. The Hispanic-serving health profession schools has a project with the CDC to develop its faculty data bases. There has never been an attempt to identify doctors in this country who are involved in minority research, and I would imagine that historically black colleges and universities have done a great job in knowing that about their own faculty but I think that for the Hispanic community in this country this is the first time that we are attempting to identify resources, our human capital resources among our own faculty to do research on Hispanic health.

The National Hispanic Medical Association has developed a leadership program for doctors, and this is another area that this report leads us to believe that HHS needs to start thinking about supporting leadership, not only within its ranks but the leadership of minority communities so that they understand how to access or how to improve access programs, outreach programs, enrollment programs and that we have middle managers as well as physicians learn how to work hand in hand with the government at the Federal and State level in matters of leadership development.

We also have for future data collection and research, and this is the last set of recommendations, there is a real need for collaboration among the research agencies at HHS on the importance of minority research, cultural competence research, and I think, as was stated earlier, especially community-based research where we include the community in helping to design and develop new strategies and interventions and study those hand in hand with researchers and academic institutions. I think Dr. Ruffin mentioned earlier about that cultural competence research in the future and Dr. Clancy talked about the EXCEED programs, and these are examples of programs that are very much needed to be expanded for research.

The National Hispanic Medical Association has established a foundation, the National Hispanic Health Foundation, and we soon will be developing plans to do health services research targeted for Hispanic, understanding Hispanic community issues. We will be working with the New York University's Wagner Graduate School of Public Service, and we look forward to helping to develop more knowledge about the Hispanic community, and I think that's one of the wakeup calls of this report is that we don't know enough about interventions and strategies. We know that there's a huge, huge problem and it's ironic that on the verge of a huge demographic change in this country where everybody is going to realize that minority health is important and that main stream America has recognized that minority health is important we need to do something about it and we're here to help. So we're here to help with again reaching out to our communities and being a link to get more information and more leaders for the government.

[The prepared statement of Dr. Rios follows:]

**National Hispanic Medical Association
Hispanic-Serving Health Professions Schools, Inc.**

Testimony

To the

**Subcommittee on Criminal Justice, Drug Policy
And Human Resources,
Committee on Government Reform,
U.S. House of Representatives**

May 21, 2002

**Elena Rios, M.D., M.S.P.H.
President, NHMA
CEO, HSHPS
1411 K St., NW, Suite 200
Washington, DC 20005
(202)628-5895**

Chairman Souder, Congressmen, HHS Officials and guests, it is an honor to be here today. The National Hispanic Medical Association (NHMA) represents licensed Hispanic physicians in the United States. The mission of the NHMA is to improve the health of Hispanics. I also work for the Hispanic-Serving Health Professions Schools, Inc. that represents 22 medical schools and 3 public health schools. The mission of this organization is to develop Hispanic student and faculty and research capacity to improve Hispanic health.

The IOM Report, "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care" discusses disparities not due to access-related factors or clinical needs and provides a tremendous amount of evidence that the U.S. health system does not adequately meet the needs of minority patients.

Hispanics are now 14% of the US population and by 2050, one out of every four Americans will be of Hispanic origin. In the case of Hispanic patients, we are challenged by the language needs, literacy levels, lower levels of poverty and education, citizenship status, cultural beliefs and attitudes, family group decision-making, awareness of public health programs or how to follow complex treatment regimens, drug labels, where to go for further tests, xrays, or specialty care in a health system. Our health system is the best in the world; but in order to be proud of that system, this report challenges us to develop new strategies to improve the quality of healthcare delivery.

I would like to address proposed strategies for the Department of Health and Human Services to continue to decrease race and ethnic disparities in healthcare.

DIVERSITY IN MEDICINE

The United States Federal government has taken the lead to recruit and retain minority and disadvantaged health professional students since the 1960's, when it was recognized that it is a Federal government role to develop programs that provide healthcare services for vulnerable population groups –Medicare for the elderly and disabled; Medicaid and Community Clinics for poor patients, and the National Health Service Corps and the Health Careers Opportunity Program for poor, disadvantaged or minority students to become health professionals for these communities. In the 1980's, HHS further developed the Centers of Excellence and the Faculty Development Program for minority students at medical schools. Through its curricular efforts, COEs impact the cultural competency of all their graduates. In addition, both these programs have increased the number of minority faculty that address research and curricular issues related to minority patients and communities.

The literature demonstrates many examples of studies on the outcomes of minority health professionals serving a major need in the U.S., namely that they provide health and mental healthcare services for minority patients of their own ethnicity and for those on Medicaid or uninsured.

HHS Health Resources and Services Administration's Health Careers Opportunity Program and Centers of Excellence Program have proven track records of graduating 2-3 times more disadvantaged and minority students than the other health professions institutions. However, for the second year, the Bush Administration has called for drastic down-sizing of these programs. We believe strongly that the IOM is a reminder for us, with the changing demographics and continued immigration of Hispanics, especially, to

recognize the critical need for minority physicians. Currently, Hispanics are only 5% of America's doctors and only 2% of America's nurses. Both the HCOP and COE programs should be expanded with increased funding at the level requested by the Congressional Black, Hispanic and Asian Caucus - \$40 million each.

We propose a new strategy: that these programs be expanded into PUBLIC-PRIVATE PARTNERSHIPS MODELS led by HRSA. The medical schools have institutionalized recruitment and retention programs, but they should be required to provide matching funds and fundraising efforts to increase the support for HCOP. We support the request from the Congressional Black, Hispanic and Asian Caucuses to increase support to \$40 million for HCOP and COE programs. Why shouldn't a recruitment program be linked to academic enrichment in middle schools and colleges through a Scholarship incentive program for minority students linked to their annual academic performance? Scholarships could be linked to the students who would be linked to programs developed at certain schools in regional consortia. And why shouldn't businesses, especially the HMOs, hospitals, pharmaceutical companies, medical suppliers and medical groups that are employers and business partners who directly benefit from their linkages with physicians, be fiscal partners in the education process of future physicians?

We recommend increased data collection and monitoring of the alumni of the program that demonstrates the extent that they provide healthcare services to minority communities and link their location of practice to medically underserved area or health professions shortage area, as does both the community clinic and National Health Service Corps programs. We recommend mentoring program development with practicing community physicians and community-based experiences

Furthermore, Medicare GME funding for teaching hospitals should be linked with a policy focus to incentives to produce minority physicians and to decrease physician practices that result in disparities in treatment and management for minority patients.

The COE program and the faculty development programs should be expanded, including loan repayment to provide incentives for more minority faculty in the health professions.

In addition, minority physicians should be encouraged to sign-up for the National Health Service Corps and President Bush's Medical Reserve Corps, not only to focus on Bioterrorism preparedness, but, to assist in the recruitment of minority students to medicine. Lastly, NHMA, the NMA, HSHPS and AMPS, and the AAIP as well as mainstream medical associations – the AAMC, AMA, AAFP, AAP, SGIM, ACP-ASIM, etc. should advocate for the development of diversity programs in medicine that are well documented and evaluated and show performance outcomes.

CROSS-CULTURAL EDUCATION

Currently, medical schools are mandated by accreditation rules to teach cultural competence to all future physicians.

The HSHPS members focus their curriculum development on cultural competence. NHMA has launched its cultural competence guidelines project, documenting Hispanic physicians' best practices on our website (www.nhmamd.org) to

provide care for Hispanic patients. We recognize the critical need for physicians and medical students to be trained on how to respect and communicate with Hispanic patients, because there will never be enough Hispanic physicians to care for the growing Hispanic population.

HHS should convene medical school leadership to discuss the IOM Report challenges about Hispanic patients for future physicians ---to train about perceptions, self-awareness, knowledge about minority groups, Hispanic culture and lifestyle, family centered, community centered, and skills for communication, dealing with interpreters, interviewing about migration status, generational status, occupational status, health beliefs, alternative medicine, the Hispanic Paradox, etc.

We recommend the funding of the HRSA Cultural Competence Curriculum Demonstration Grants that were part of the Health Care Fairness Act of 2000 as well as fostering cultural competence training development by NIH Center for Minority Health, Agency for Healthcare Research and Quality, and the Centers for Medicare and Medicaid Services – so that the Federal government prompts the system to meet its own Culturally and Linguistically Appropriate Services Standards set forth by the Office of Minority Health in 2001.

LANGUAGE SERVICES

I ask you to consider the following: A Spanish speaking family brings an ill baby to an emergency room and cannot communicate with the ER staff. The baby has a fever and is sent home with Tylenol. Another Spanish speaking family brings an ill baby with similar symptoms to an ER with Spanish-speaking staff and the baby is admitted with a diagnosis of appendicitis, is observed with worsening abdominal guarding and has emergent surgery and her life is saved.

Hispanics are reported to speak more Spanish, especially when in the health system. It is also well known, that the use of Spanish language is passed on generation to generation, especially in the more marginalized families and neighborhoods that are isolated, more stressed, more dysfunctional and less healthy (physically and mentally) patients. So the problem is exacerbated for the health system and urgently needs attention.

The White House OMB concluded in its report on assessment of implementing services to Limited English Proficient (LEP) persons, that the benefits seem to outweigh the costs since language services improve access to and can increase effectiveness and distribution of public health programs. Moreover, language services will substantially improve the health and quality of life of LEP individuals and their families.

We propose that HHS support demonstration programs through HRSA, SAMHSA and Centers for Medicare and Medicaid Services to provide incentives to prepare to improve the medical delivery systems of the future.

Interpreter services should be developed for bilingual staff, bilingual providers as well consultant interpreters that should be developed as new auxiliary health positions with certification and training programs. Spanish language training for providers (including CME programs) and for medical students should be supported significantly in

targeted markets. There is a critical need to develop reimbursement policies for these and new technologies that are affordable, especially Medicare and Medicaid.

A new program for managed care partnerships in targeted states as incentives for Medicare programs to expand services to elderly Spanish speaking could be developed for language services and Spanish training of providers.

All of HHS prevention literature and website materials should be increased with Spanish language information.

Media, both English and Spanish, TV, radio, internet, and print, needs to be partnered by HHS to develop targeted public education about health care services and programs.

SYSTEMATIC STRATEGIES

Hispanic-Serving Health Professions Schools, Inc. Faculty Clearinghouse

This project is funded by the CDC for 5 years to develop a mechanism to educate faculty who work for the medical school and public health school members of the HSHPS on opportunities to decrease race/ethnic disparities in healthcare – for EJS and other public health professional advanced training, new grants for minority research, and invitations for Federal conferences, meetings and peer review committees.

National Hispanic Medical Association Leadership Fellowship

This program, a joint effort with the Robert F. Wagner Graduate School of Public Service, was sponsored by HRSA for 3 years. The NHMA Leadership Fellowship Program has been an outstanding success. The Fellowship has promoted the development of leadership potential among 60 mid-career Hispanic physicians from across the nation in 3 years. The program offers a unique health policy leadership development curriculum that has been enthusiastically received by faculty and Fellows. Through the program, we have expanded awareness of important Federal programs, how Congress and the Executive Branch work, as well as awareness of other sectors that impact on health issues that impact Hispanic community through networking with media, foundations, national advocacy organizations and key leaders from different sectors of the health arena. The Advisory Committee, consisting of public health leaders from across the nation, have served as mentors and speakers in the program.

FUTURE DATA COLLECTION & RESEARCH

The Agency for Healthcare Research and Quality, the Centers for Disease Control and Prevention, the Centers for Medicare and Medicaid Services and the National Center on Minority Health and Health Disparities should collaborate on their data collection and Disparities Research programs to build strategic requirements of grantees and to build major minority health research centers. Congress should expand this area of critical research which is a cross-cutting activity that has limited support compared to biomedical research. Without new knowledge with community-based research, we will

never advance beyond the disparities that now exist in the health care system. In addition, states and health surveys and health facilities should be mandated to collect data by race and ethnicity and language use and conduct interviews and have materials in Spanish in order to develop a quality health care system.

Office of Minority Health at each agency at HHS should be supported to provide a collaboration in oversight with these activities and others to promote the goals of the Department targeted at minority populations.

The NHMA established the National Hispanic Health Foundation, a 501(c) 3 organization, to develop health services research and policy analysis to focus on such issues as disparities in the health system, cultural competence, language services and health professions diversity. We are currently negotiating the location of the Foundation at the Robert F. Wagner Graduate School of Public Service, New York University, the largest graduate health management/public service training program in the U.S. with researchers already engaged in Hispanic research. The Foundation would also be linked to the NYU Medical School, which also has a strong interest in Hispanic health research.

The following are the major activities that the Foundation would address:

- 1) Health services research targeted at Access to Health Care, Quality Health Care, Cultural Competence, and Language Services for Hispanic populations across the United States. This research would be done by researchers at the Wagner School and key Hispanic researchers at sites around the country.
- 2) Research Scholars Program for Senior Hispanic researchers on sabbatical from their universities to learn about policy related research for Health.
- 3) Research Training Institutes for Junior Hispanic researchers. We need Hispanic researchers desperately who understand the nuances of their communities and can develop new knowledge for Hispanic health development, at the national and state levels.
- 4) Journal of Hispanic Health. One does not exist in the United States and a peer-reviewed journal would target the physician readers and CME programs so that they can better understand the issues of Hispanic health.

In summary, we need to raise awareness of Hispanic and minority health issues through research and documentation and publication. I believe that these efforts are unique and will offer outstanding information to move the policy and research arena forward for Hispanic health program development.

CONCLUSION

The IOM Report on Unequal Treatment is a wake-up call to America that its health system needs to be fixed. It is ironic that on the verge of a major demographic change, when the workforce will become more minority, in order to maintain a healthy economy, we must prepare to turn the Disparities in Health Care around by developing and enhancing STRATEGIES now. By decreasing disparities for the minority patients, we increase the quality of health care for all Americans.

REFERENCES

Keith (1985, *New England Journal of Medicine*) found that minority medical graduates practiced in federally designated health-manpower shortage areas almost twice as often as non-minority graduates. He also found that minority physicians tended to serve members of their own racial or ethnic population group more than members of other groups.

Moy and Bartman (1987 *National Medical Expenditure Survey*) that minority patients were more than four times more likely to receive care from non-white physicians than were white patients not of Hispanic origin. Low-income, uninsured, and Medicaid patients were also more likely to receive care from non-white physicians.

Kamaromy et. al. (1993 *New England Journal of Medicine*) reported that Black physicians practiced in areas where the percent of Black residents was nearly five times higher than in communities where non-Black physicians practiced. Similarly, Hispanic physicians practiced in areas where the percent of Hispanic residents was twice as high as in areas where non-Hispanic physicians practiced. Hispanic physicians cared for three times as many Hispanics and for more uninsured patients as did other physicians.

Tocher and Larson (1999 *Journal of General Internal Medicine*) reported that there were no differences in the time physicians in a general medicine clinic in the state of Washington spent providing care to non-English speaking patients and English-speaking patients.

Office of Management and Budget, White House: "Assessment of the Total Benefits and Costs of Implementing Executive Order 13166: Improving Access to Services for Persons with Limited English Proficiency."

HHS Office of Civil Rights, *Guidance on Limited English Proficiency*

Doty and Ives, "Quality of Health Care for Hispanic Populations: Findings from The Commonwealth Fund 2001 Health Care Quality Survey," March 2002.

Morales, et al, "Are Latinos Less Satisfied with Communication by Health Care Providers," *Journal of General Internal Medicine*, July 14, 1999, 409-416.

Mr. SOUDER. Thank you for your testimony. We've been joined by Dr. Thomas LaVeist. I need to swear you in. If you'll stand. The subcommittee as an oversight committee requires it.

[Witness sworn.]

Mr. SOUDER. Let the record show that the witness responded in the affirmative. Thank you for joining us and we'll let you have 5 minutes for your testimony and we'll insert anything you don't get covered into the record or any additional materials.

Mr. LAVEIST. Thank you. I beg your forgiveness for returning late from recess.

Mr. Chairman, honorable members, thank you for inviting me to participate in this important hearing. The recently released Institute of Medicine's report on racial disparities and health care summarizes decades of research that has not always received the attention that it deserved.

I have devoted my career to further understanding the issues of racial disparities in health, and I am pleased by the response that has come from this report. I am encouraged that later this year Johns Hopkins University along with Morgan State University will announce the creation of the Center for Health Disparities Studies, and the goal of that center will be to bring together—bring to bear the resources of both institutions to address this very important problem.

According to the Census Bureau, in the coming decades American racial and ethnic minorities will be an increasing proportion of the national population and eventually become a majority. As such, the health profile of the country will increasingly become reflective of its minority population. The United States already has a surprisingly low international standing with regard to health status. We are already No. 17 in female life expectancy and No. 26 in the world in infant mortality. This is only one spot above Cuba. Without a reduction in and elimination of health disparities our international standing in terms of health will most likely be even lower in the coming decades. This will have an important negative economic impact as well in terms of lost wages and productivity due to disability. And the impact on the Federal and State budgets is predictable, increasing Medicare and Medicaid costs, and we can't ignore the impact that increasing health care costs will have on the private sector.

While the IOM report is important, this is not the first published report documenting disparities and even discrimination in health care. This is not even the first such report written by the IOM. So why am I so hopeful that this time the issue will not again lose momentum and exit the national agenda? The reason for my optimism is that I believe there is the potential to establish a national infrastructure to address race disparities in health. Creation of the National Center for Minority Health and Health Disparities is among the most important improvements to our Nation's health care infrastructure in decades.

As one who has been conducting research on minority health and health disparities for many years, I want to take this opportunity to thank Congress for its leadership in creating this center. This new entity will play a central role in ensuring that the issue of minority health and ill health remain on the national agenda. But we

must not stop there. American public health and medical researchers have sustained a steady march toward the furtherance of our understanding of the causes of premature death, ill health and preventable disability. But while we have been leaders in furthering knowledge and health status and curing disease, we have been less attentive and some might even say accepting of pervasive disparities in health.

Why is it that American minorities live sicker and die younger? Certainly the answer is complex and elusive, but there are a few things that we do know. We know that it is unlikely that the answer lies in biology and is exceedingly unlikely that a solution will come from genomics. Likewise, programs such as Take a Loved One to the Doctor Day, which was recently proposed by the Secretary of Health and Human Services, misses the mark and will have little efficacy. Increasing the number of minority health care providers is needed, but this alone will not solve the problem.

The weight of the evidence I believe indicates that the causes of persistent and pervasive racial disparities in health lie in the actions and inactions of individuals and the inequitable outcomes within health care organizations and health systems. Health care lags behind other government-regulated industries in that health care has not addressed racial discrimination since the desegregation of hospitals. Housing, labor, education, criminal justice, these areas all have ongoing systems in place to monitor, measure and sanction documented discrimination. In contrast, there are many hospitals that do not even collect data on patients' race.

Why? Well, my contribution to the IOM report was to outline the basic parameters of the development of a civil rights monitoring program in health care. Monitoring systems are not unprecedented in health care. There are existing monitoring programs for health care quality, patient satisfaction, and there are report cards on health systems. A health care discrimination monitoring and enforcement system similar to efforts in housing will not likely be the solution to disparities in health care, nor will it solve all health access problems. However, such a system will help us to move toward equity in health care equality and likely reduce disparities in health care outcomes and improve health status.

Thank you.

[The prepared statement of Dr. LaVeist follows:]

CONGRESSIONAL TESTIMONY

April 21, 2002

Thomas A. LaVeist, Ph.D.
Associate Professor of Health and Public Policy
The Johns Hopkins University
Bloomberg School of Public Health

624 N. Broadway
Baltimore, MD 21205

tlaveist@jhsph.edu
410-955-3774

Thank you for your invitation to participate in these important hearings. The recently released Institute of Medicine report on racial disparities in healthcare summarizes decades of research that has not always received the attention that it deserved. Health disparities are a manifestation of the remaining vestiges of the underlying differences in the quality of life and opportunities of American racial minorities. I have devoted my career to furthering understanding of the causes of racial disparities in health. I appreciate this opportunity to participate in your efforts to find solutions.

While the IOM report is important, this is not the first published report documenting disparities and even discrimination in healthcare. This is not even the first such report written by the IOM. So why am I hopeful that this time the issue will not, again, lose momentum and exit the national agenda. The reason for my optimism is that I believe there is the potential to established a national infrastructure to address race disparities in health.

Creation of the National Center for Minority Health and Health Disparities is among the most

LaVeist

important improvements to our nation's healthcare infrastructure in decades. As one who has been conducting research in minority health and health disparities for many years, I wanted to take this opportunity to thank the Congressional Black Caucus, and Congress in general, for your leadership in creating the center. This new entity will play a central role in ensuring that the issue of minority health and ill-health remains on the national agenda.

But, we must not stop there.

American public health and medical researchers have sustained a steady march toward the furtherance of our understanding of the causes of premature death, ill-health and preventable disability. But, while we have been leaders in furthering knowledge in health status and curing disease, we have been less attentive – and some might even say accepting – of pervasive disparities in health.

Why is it that African Americans live sicker and die younger than all other American racial and ethnic groups? Certainly the answer is complex and allusive, but there are a few things that we do know. We know that it is unlikely that the answer lies in biology and it is exceedingly unlikely that the solution will come from genomics. The weight of the evidence, I believe, indicates that the causes of persistent and pervasive racial disparities lie in the actions and inactions of individuals, and the inequitable outcomes that result from organizations and health systems.

LaVeist

Healthcare lags behind other government-regulated industries in that healthcare has not addressed racial discrimination since the desegregation of hospitals. Housing, Labor, Education, Criminal Justice. These areas all have ongoing systems in place to measure, monitor and sanction documented discrimination. In contrast, there are many hospitals do not even collect data on patient's race.

Why? My contribution to the IOM report was to outline the basic parameters for the development of such a program in healthcare.

Monitoring systems are not unprecedented in healthcare. There are existing monitoring programs for healthcare quality, patient satisfaction and report cards on health systems.

A healthcare discrimination monitoring and enforcement system, similar to efforts in housing, will not likely be the *solution* to disparities in health status. Nor will it solve healthcare access problems. However, such a system will help us to move toward equality in healthcare quality and likely reduce disparities in healthcare outcomes and health status.

Mr. SOUDER. I want to thank each of the witnesses once again for your patience. This has been a long afternoon for your testimony, and working with it, I would strongly encourage each of you as you work with this and as you work with the agencies and with Congress to make sure—I don't think any of us would deny regardless what political party, maybe some are less inclined, that discrimination in fact occurs. But in order to address it we need to know where it is discrimination based on race or ethnic backgrounds and where it's discrimination based on income, cultural, education, language, and to make sure that where possible, it may include marriage differentials, in trying to figure out how best to address where the root problems are in the differentials we have to make sure we have the right mix of scientific data.

One thing is that you have to collect it. I think that there are several other things that I want to make sure that I put in the record. I know one of the problems with medical coverage in a lot of our urban areas has to do with the medical malpractice insurance. And we have to address that question because the cost disparity in those places for a physician to come in is huge, that over the years—I mean there are just tremendously underserved and that's one of the cost pressures of any doctor looking at coming in. We need to be fair to the patients and at the same time not have that be a distraction.

I think another kind of fundamental thing that I've seen in the emergency rooms, in particular, is the bill collection process, where the hospital collects different from the doctor, which collects different from the other testing procedures, is chaotic no matter what your background is. If you're trying to manage a limited amount of income to try to figure that out and think you paid the bill then another bill comes, just at a gut level having gone through different things in the emergency room and talking to different individuals, this is a much bigger problem than is acknowledged because the bill collection percentage is really low in some areas. And it's why hospitals financially are moving more toward suburban markets and they find a financial disincentive in some of the doctors. We have to figure out where those gaps are in the system and how to address those gaps, because if we aren't reflecting what is actually occurring at the grass roots level it becomes very difficult even while we may be able to force someone by saying, which I support, if you're going to get a student loan you will underwrite a certain portion to go to a low income-served area. The second they fill their requirement in 3 years they're gone. If we can't make it so they can figure out how to survive long term, we need to address those questions.

I have a couple of specific questions for Dr. Cooper and then if any of you want to comment on the remarks that I made. I thought it was interesting and logical that primary care patients in race concordant relationships rated their physicians as being more participatory than those in race discordant. Were the statistics at a level enough to be statistically reliable?

Dr. COOPER. Definitely they were. In fact, in the study that I mentioned that took place in this area in Maryland, Virginia and the District of Columbia the differences between patients and race concordant and discordant relationships were of a magnitude such

that they predicted at least a 10 percent increased likelihood that a patient would disenroll from the physician's practice over 1 year. So it was statistically significant, but also likely to be clinically significant as well.

Mr. SOUDER. Is that true in African American, Hispanic, Asian and all groups?

Dr. COOPER. That was in all groups that we looked at.

Mr. SOUDER. Are you able or were you able to in any way separate that statistic to see how much of it was language and how much of it was—in other words, let me give you an example in veterans hospitals. Veterans prefer to go in many cases to a veterans hospital because they perceive that they're treated differently, different respect and some of them are what I would call maybe psychological variables which are still real. Others are actual barriers because of language questions.

Dr. COOPER. We actually did not ask about language. You know, all of these patients were proficient enough in English to respond to the survey. So it would suggest that these people were not people who were experiencing extreme language difficulty. There's been other work that shows that minority patients will say that they prefer a physician of their same race or ethnic group and that will occur aside from language similarity, that language concordance is something that contributes to that, but not totally.

Mr. SOUDER. Do you find, and I know this an explosive question, I'm just asking to see whether the data reflected this—is this predominantly an anglo ethnic or would this apply to a Hispanic group with a Hispanic—with a black doctor, an Asian group with a Hispanic doctor?

Dr. COOPER. Right. We actually looked at physicians of different races to see where the stronger effect was, and we found that within each race group the physicians who were seeing patients of their same race were rated more highly with the exception of Hispanic physicians, where we didn't achieve statistical significance but we had a much smaller number of Hispanic physicians in the sample. So it seems it's not a finding that is limited to one specific ethnic group, but that all ethnic groups, patients of all ethnic groups will express this increased satisfaction or partnership when there's a similar race physician, which leads us to believe that there's something about the relationship and the rapport that may have something to do with cultural similarities or similar social experiences, something else that we haven't quite captured, some trust between people that is based on, you know, just comfort level and expectations of being understood and treated well.

So what we'd like to do is see what we can learn from this. We think it suggests that we need more diversity among health professionals, but it also suggests that maybe there's something we can learn from these same-race relationships. Is there something that goes on in those relationships that we can use to teach other people so that when they're relating cross-culturally and interculturally that they can emulate those same behaviors and attitudes.

Mr. SOUDER. It's really an important point because I think while we'll try to continue and we need to continue to try to recruit more minority people into the health care, the truth is particularly when you get into a mid-sized city as opposed to large city the base of

the sub-communities are not big enough with which to sustain all the diversity. For example, in Ft. Wayne, which is 200,000, 300 in the metro area, in the south side of Ft. Wayne in the community health center, which has historically been African American—I think it's now down to about 25 percent, maybe 40 percent Hispanic, another 15 percent Burmese and another 5 to 10 percent Bosnian with hardly any Anglo in it, and yet it's not big enough to sustain a doctor in each one of those subgroups and a nurse in each of those subgroups. So we have to figure out how to cross-train because even if we expand it it's not clear that a minority person who is in that area will be of the minority, particularly since neighborhoods shift. One of the areas that for some reason we have whole lot of Bosnians who came into my area and we have the largest Burmese population in the United States. It was 400, now there's over 2000. So when they move that a neighborhood it changed substantially who would be providing the health care to them. And they don't—many of them don't speak that much English. And it is—we've never had a Burmese population before, so it's kind of a new phenomena that the whole community is working through. The Mexican immigration is easier and Central and South American immigration because we're dealing with languages but in some of my school districts they have 22 languages in rural Indiana. So you know that this problem is becoming increasingly challenging all over the country.

Dr. COOPER. I think what we're trying to do is to learn exactly what cultural competence is. What does that mean? And are there some generic skills that the students and health professionals need to have in order to interact effectively regardless of who they're interacting with, you know. Because—and I think we cannot over simplify the fact that a person is from the same race or ethnic group doesn't mean that they're necessarily going to hold all the same beliefs and values as well. So I think we're trying to understand more from our research what this cultural competence phenomenon is so that we can actually teach it in a more effective way. And we need to teach it and also to evaluate how our teaching is impacting on care and our outcomes.

Mr. SOUDER. Mr. Cummings.

Mr. CUMMINGS. Dr. LaVeist, do you—how much faith do you have in this National Center for Minority Health?

Mr. LAVEIST. I do think it's very important. I do have faith in it, because what that center does is tries to cut across the various institutions at NIH. NIH is set up in a disease specific way. But the issue of race disparity is not disease specific, it's not so much cancer or heart disease or stroke, it's all that. I think a center that cuts across the various health outcome mandates of those institutes I think is the right configuration. My faith is I guess entrusted in—my faith is operating under the assumption that it will continue to be funded at an appropriate level and as such be able to do things like develop these research centers and fund these centers appropriately so that these centers can continue to do the kind of research that needs to be done.

Mr. CUMMINGS. You were here a little bit earlier and you heard the testimony of how certain things were being cut back with regard to the—

Mr. LAVEIST. HRQ.

Mr. CUMMINGS. Yeah. And how that seems to fly in the face of all the things that we're talking about here today. Did you have a comment on that, Dr. Rios, on what I just said?

Dr. RIOS. Oh, sure. I couldn't agree with you more. I think it is a time, a very difficult time right now when the Federal Government is committed to healthy people 2010, which is still another 8, 9 years away. We've got all the States involved with trying to focus in on collecting race data now, collecting subgroup data for Hispanics. Now we have a new census, a 2000 census, that shows us that we've got markets in different countries, as the chairman alluded to, markets where we haven't seen minority populations live. We have a health care awareness of the need for language and culture to make a quality health care. And in spite of that, the funding for I think what is very important, research and preparing for the future, is being targeted for major cuts. And the health professions too, I have to throw that in. I think that we need to think about how to have a cross-cutting approach to HHS when we talk about disparities. And there are things that do work.

There are programs that are working that have proven successful for increasing minority health. Only nobody's ever looked at them together. The National Health Service Corps that you mentioned, there should be a more targeted approach to people that come from certain communities to—and I'm from California, and in California there's a State-based, a State Health Service Corps Program, so that the doctors would pay back their student loans but stay in the same State. And there was more of a chance at that time doctors would go working in community clinics and certain communities and staying in those States because they're from the area.

Mr. CUMMINGS. Dr. Cooper, when you—you know, I was talking about this study on the radio in Baltimore, and I was trying to figure out what the listening audience could do themselves because the report sounded so bleak. And when I look at the funding situation, I mean I'm trying to figure out what do you say to a patient or people who—because there are a lot of people who are sick and don't even know it. And I mean, do you tell them to go and get—I'm not trying to take the weight off the government because we're supposed to do what we're supposed to do, but in the meantime what do you say to a patient. If you had a patient that had read this report and understood it, and the patient says, well, what advice do you have for me and for my family, I mean, because according to the report you got insurance, I mean apparently you know how to get to a doctor, these people, and I'm talking about as far as the study is concerned, I mean what do you say to them? They can't just go up to say, look, are you a racist or what? So what do you say? What would you as a doctor say?

Dr. COOPER. I think what I try to say to my patients is, well, first of all, I try to ascertain from them what their level of interest is in advocating for their own health and try to encourage them to become more active in this, engaging in more healthy life-style changes and in healthy behaviors. But I also encourage them to become more involved in learning about health and encourage them to ask questions when they don't understand. I think this is part of what we're talking about when we say improving intercultural

communication. We're talking about cultural sensitivity and reducing stereotyping behavior and bias, but we're also talking about just using good communication skills, which will allow people to express what their concerns are. So just asking people what's your understanding of what's wrong with you and trying to assess where they are with that and can you tell me why you think you have kidney failure and what do you think would help in this situation. And so trying to understand what people's own understanding of their illness is and what they think would work for them and then working with them based on their own social and family situation, but trying to get them really engaged in the process, because we know that's the only thing that's going to allow people to make changes in their behavior.

Mr. CUMMINGS. Do you say to the person, the African American person who this report says has the 3.6 times chance of having an amputation if he's got diabetes—I mean what do you say to that person when they come to you and say, Doc, I read this report, and it's a lady, and she says I love my legs but now they're saying I've got it? And this is very real.

Dr. COOPER. I am concerned about the impact of this report on the doctor-patient relationship. I think it's very important that we're looking at these problems, but I also am concerned that the way that the message is portrayed is not such that it causes more distrust between patients and providers. I think what I would say to people is that you know, I think the majority of health professionals don't go into this field so that they can discriminate against people, that a lot of these people are well-meaning people that have good intentions, and what it is is that people are just not aware of their own biases. And so although I believe the burden of responsibility is on health professionals first and foremost, I think that patients can play a role if they're more informed about what is going on and they know what is appropriate for them. So if they can get information, ask for someone who is an educator or case manager to explain to them what should I be getting if I'm a diabetic patient, what kind of treatment should I be receiving that I'm not receiving, you know. Am I on the right medication that I should be on? Am I on the right dose? What should I be asking my doctor to help me do so that I don't end up with an amputation? And letting them know that they do have a right to ask those questions and to request, you know, certain things.

Mr. CUMMINGS. But tomorrow my leg is going to be amputated. My leg is going to be amputated, Doctor, and I know that as a black person I have a four times, almost four times greater chance. I mean that's the rest of their life you're talking about, quality of life you're talking about, you know, having to go around this a wheelchair. See, and that's what make the report so—and I agree with you. I'm concerned about the other end of it, too. But when these people call me and say what are we supposed to do, you know, that kind of stuff is just so wrenching. I think government has to, we've got to do more. We've got to find ways—I've often said, and I'm sure the chairman agrees with me, we've got to spend the people's tax dollars effectively and efficiently but we've got to find ways in that mode of effective and efficiency, we've got to find

ways to try to prevent some of the catastrophes that this report says are happening every minute of almost every day.

Dr. COOPER. And I think it's going to have to take place on several levels, you know, like the chairman mentioned. Financial incentives for providers need to be changed. I think from the patient perspective, doing everything they can, having them know that they do have a right to question what's being done to them and that they can request a second opinion, they can bring in a family member, or they can call someone else who they know who might be more familiar with the health care system and ask their opinion as well, that they're entitled to that. I think if there's anything we can do it is to educate the public that this is a problem and that you do have a right to question this and to ask for the best quality health care because it's available here in America. It is here and it's a question of actually advocating more actively for it whenever possible.

So, but again I feel like that we can educate and activate people up to a point, but really the burden is on the system and on the professionals to take the lead in that role.

Mr. CUMMINGS. Finally, there were three things that you all would want us to do, Dr. Rios. What would those three things be? I mean top priority. If the Congress said there are three things that we're going to do, we may not be able to do all this other stuff that is recommended, but the things that come under our purview, what would be the three top things off the top that you would want to see us do?

Dr. RIOS. No. 1 is universal access. I think if we can have public education, and this system may not be the best, public schools in certain cities, depending on the teachers and the curriculum, but we certainly have an opportunity for education. And in this country we don't have an opportunity for health care. That's part of the big problem for disadvantaged and immigrants and Hispanics and other minorities. That's No. 1.

No. 2 I think is more research that's community based and targeted approaches and intervention so you can measure and understand with a small study what works, what doesn't work. The interpreter services, right now the Robert Wood Johnson Foundation just started the new project of La Muz Huntos to do that. They're looking at cities where it's an emerging problem to understand how to work with doctors that have never worked with Spanish speaking patients before.

So I think I know we need community based research, targeted, demonstration models, with minority consumers and minority providers working with the government. And the third thing is we need the minority doctors, because what we don't have is the minority physicians to document the cultural competence and the best practices. For years we've had doctors working in small mom and pop private clinics, private offices. I am from the East L.A. area, they're still there, volume cash paying patients. It's a whole underground market. There's no licensing from—I mean there's no data collection from the State because the State only collects from licensed clinic, licensed hospitals, licensed nursing homes. These are private businesses. Managed care doesn't touch the underground that exists in our minority communities. Doctors provide care be-

cause there's a demand. But there's no documentation of what are the best practices and how those doctors do get those patients, and generations after generations of families after families coming back to the same doctors. And that's the quality care that we need to understand and meld with our academic health centers, where a lot of minority patients go there, you know, because there's training going on of young residents.

Mr. CUMMINGS. Thank you very much.

Mr. SOUDER. I want to thank you all for participating and thank Mr. Cummings for seeking this hearing and working with us. I found it very informative, and one of the primary reasons we did this is we know we're never going to fully fix our health care system and people are always going to complain and the hopes and dreams of a perfect health care system outstrip our ability to pay for it and the new inventions of everything from drugs to facilities that are unimaginable at this point. We don't even know what's going to be invented tomorrow, and our expectations and the reality of it need to be addressed.

We also know we have huge immigration questions in this country, that we've always had them, but right now they're of particular attention and we have to work that through, which is a subpart of what you're doing.

I felt this hearing was also especially important because whether or not we get more than 59 percent happy with the health care system may or may not be achievable long term, but what we do know is there shouldn't be a 20 percent disparity. And even in those statistics, 59 to 50 and 40 something to 40, between African American and non-African American, for example, is not right. And even if the gap is closing we need to be concentrating on whatever satisfaction level we can get as a society. The gaps inside it should be minimal, and that's ultimately one of the goals of Congress. And we appreciate your help with that and Mr. Cummings' leadership.

With that, our hearing stands adjourned.

[Whereupon, at 3:40 p.m., the subcommittee was adjourned.]

[Additional information submitted for the hearing record follows:]

NATIONAL CONGRESS OF BLACK WOMEN

**Dr. C. DeLores Tucker
Convening Founder/Chair**

*African American Women and HIV/AIDS
Initiative*

September 30, 2001

Prepared by

**Dr. Patricia Funderburk Ware, President and CEO
PFW Consultants, LLC**

and

**Jacquelyn D. Jordan, Ph.D., RN
Assistant Dean, Undergraduate Program
Howard University**

College of Pharmacy, Nursing, and Allied Health Sciences

NATIONAL POLITICAL CONGRESS OF BLACK WOMEN, INC.

8401 Colesville Road, Suite 400 • Silver Spring, MD 20910-3363 • 301-562-8000 • Fax 301-562-8303



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Dear Reader:

Included among twelve items in the NCBW's Statement of Purpose is the following:

To engage in research and fact-finding on critical issues uniquely altering the quality of life of African American women and youth.

This compelling report, brilliantly researched and written by NCBW members, Patricia Funderburk Ware and Jacquelyn Jordan, Ph.D., chair of our health committee, graphically illustrates our strong commitment to living up to our declared purpose and mission.

We urge you to read it, comment on it, add to it, and most importantly, act on it.

Sincerely,

Dr. C. DeLores Tucker
Chair

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INTRODUCTION

At the dawn of a new millennium and possibly another World War, issues affecting the welfare of African American women and their families are as pressing as they were a decade ago. We still face two-fold discrimination based on gender and race. We still find too many situations in which a “first” or an “only” is expected to replace integration and equality. Sadly, one arena in which African American women have more than their share is the devastating HIV/AIDS crisis.

This report identifies the HIV/AIDS enemy as we see it. Included are descriptions of some efforts to overtake it, and reasons why the National Congress of Black Women (NCBW) feels those efforts have not been highly successful. Based on research we have obtained, this report outlines new strategies we believe will land a fatal blow to the enemy. These strategies bear some similarity to those being developed and deployed to defend our nation against a recent attack by another kind of terrorist.

For many, the reality of HIV/AIDS’ vicious and unexpected assault came in the form of shocking data from the Centers for Disease Control and Prevention. (CDC). This data graphically exposed the significantly disproportionate rates of the virus among African Americans, particularly women. We now realize that the HIV/AIDS terrorist has been insidiously invading our communities for two decades. The signs of its presence were there, but most of us were either unaware of its existence, or did not believe it was capable of such invasion and destruction. This is a different kind of enemy that only shows itself in the wake of its devastation. For example, a positive HIV diagnosis can come out of the blue before we know what hit us. It can ravage a body before we know it is even on the scene. Yes, we were warned, but some ignored the signs. Others heroically tried to fight back. Nevertheless, the billions of dollars spent in the battles of prevention, care and research have not routed the terrorist from our homeland. There are hundreds of thousands of victims now, and we are still counting.

We have no choice but to return to the drawing board to revamp our strategic war plan. African Americans are under siege, and we are now determined to respond aggressively.

First, we must know what this enemy called HIV/AIDS is.... *education is imperative*. We must know exactly where it is located...*early, routine, and in some cases, mandatory, diagnosis should be the standard*. We must then warn others of

its presence and their possible exposure to its attack.... *confidential partner notification is unquestionable*. We must be there available to help others.... *compassionate care for those infected and affected by the virus is irreplaceable*. We must strengthen our arsenal of weapons. *Comprehensive clinical research* must be accelerated to develop defensive weapons of *affordable treatments* and *a cure* for those who have already become victims; and, the offensive *vaccine* weapon to eliminate the risk of capture by this terrorist. We must employ the offensive artillery of correct and consistent *condom use* to make chances of capture more difficult. Our most powerful, effective and available offensive weapon, *abstaining from sex outside of a mutually faithful, monogamous, lifelong relationship*, must be on the front lines of attack at all times.

In order for these tactics to work, we must have an unshakeable commitment to stop the HIV/AIDS terrorist completely. It will take patience and sacrifice. It will take an unrelenting sense of faith in, devotion to and support from one another. NCBW calls for all African Americans to make a renewed dedication to protect one another by protecting yourself, and to provide compassionate care to those who have already been in the enemy's direct line of fire. We also ask that you respond in an unconventional way to this challenge. We must change many of the behaviors with which we have become comfortable. We must stop assuming that African American adolescents and adults cannot exhibit sexual self-control. We must teach our youth how to be disciplined by first modeling self-discipline for them. We must recapture our sense of pride as a people and look to ourselves to rebuild hope within our ranks. The same hope that kept us alive, sane and productive (through slavery, Jim Crowism, lynching, and segregation) is still within our reach. The success of this war depends on us.

HIV/AIDS and African American Women

June 5, 2001 marked the 20th anniversary of the first recognized cases of AIDS reported in the Centers for Disease Control and Prevention's (CDC) Morbidity and Mortality Weekly Report (MMWR). Twenty years and hundreds of thousands of American AIDS related deaths later, it is well documented that HIV/AIDS has by no means confined its venom to gay men, the population first infected in large numbers. At the end of two decades, women represent an increasing share of persons with AIDS, the most advanced stage of HIV infection. They also have an alarmingly high rate of individuals infected with HIV.ⁱ Nearly two-thirds of those women are African American.ⁱⁱ Furthermore, the negative affect of this vicious and pervasive disease is not limited to the deterioration of the physical health of our people. Virtually all areas of our existence are indirectly impacted, including individual and community economic growth, educational and career achievements and family stability.

As an organization that has African American women as its primary focus, the National Congress of Black Women (NCBW) has taken on the awesome challenge of helping to battling the spread of HIV/AIDS. NCBW will achieve this goal through awareness, education/training and promotion of effective prevention, care, research, and funding policies.

NCBW's first order of business was to learn as much as we could about the disease to determine an appropriate role for NCBW to play as a partner with other tireless fighters. It was also important for NCBW to understand why the United States, after two decades of combating this devastating virus, has not seen significant decreases in new HIV infections and a near end to the epidemic. And, above all, why does the African American community seem to be bearing the brunt of its fury now.

We discovered that there are many battles to fight in the war against HIV/AIDS. In order to be strategic and effective, NCBW has determined to focus on specific aspects of this multi-faceted problem. Progress to end the epidemic was irrefutably impeded by fear, denial, prejudice and other negative attitudes associated with a disease that deals with issues of sexuality, especially homosexuality, and drug abuse. Nevertheless, NCBW believes that these were not the greatest deterrents to limiting the spread of HIV/AIDS in the African American community. Our research indicates that a lack of sound public health policies affirmed and aggressively implemented by the U.S. Public Health Service appears to be the chief culprit.

HIV/AIDS AND AFRICAN AMERICAN WOMEN STATISTICS

According to data from the Henry J. Kaiser Family Foundation's *Key Facts Women and HIV/AIDS, May 2001*, there are an estimated 800,000 to 900,000 Americans now living with HIV/AIDS. Many of them do not even know they are infected. Though billions of dollars are spent each year on prevention programs, it is estimated by the CDC that 40,000 new HIV infections occur in the United States each year. Of those infected, a disproportionate number are African Americans. The following statistics graphically illustrate this fact:

- From the 1999 CDC's National Center for HIV, STD and TB Prevention Report
- Through December 1999, the CDC had received reports of 733,374 AIDS cases. Of those, 272,881 cases occurred among African Americans. Representing only an estimated 12% of the total U.S. population, African Americans make up almost 37% of all AIDS cases reported in this country.
- Researchers estimate that 240,000 – 325,000 African Americans – about 1 in 50 African American men and 1 in 160 African American women – are infected with HIV.
- 21,900 cases were reported among African Americans, representing nearly half (47%) of the 46,400 AIDS cases reported in 1999.
- Almost two-thirds (63%) of all women reported with AIDS were African American.
- African American children also represented almost two-thirds (65%) of all reported pediatric cases.
- The 1999 rate of reported AIDS cases among African Americans was 66.0 per 100,000 population, more than two times greater than the rate of Hispanics and eight times greater than the rate for Whites.
- As of June 2000, young black females between 13 – 19 years of age represented 73% of all (but who had not developed AIDS) young women in this age group diagnosed with HIVⁱⁱⁱ.
- Data have shown high HIV infection rates among blacks since HIV testing began in 1985.
- The CDC reported in the July 26, 1990 New England Journal of Medicine that of nearly 90,000 Americans tested anonymously for HIV in 1988 and 1989 at 26 hospitals in 21 cities, the rate of infections in blacks was approximately twice that of infections in whites.
- Job Corps test results in 1988 showed African American men to have HIV infection rates roughly four times higher and African American women seven times higher than their white counterparts.^{iv}

- From 1985 to 1988, military data, which represented a much larger number of young people from more diverse communities, showed much higher rates of HIV infection among African Americans applying for active duty, as well as among those presently serving their country. The rates for Blacks exceeded four times that for Whites. Incredibly, even then, black women had a higher rate of HIV infection than white men.⁵
- Data on HIV and AIDS diagnoses in states with integrated reporting systems show the trends of disproportionate HIV and AIDS infections among Blacks are continuing.

HIV/AIDS REPORTING

HIV is the beginning stage of the HIV/AIDS disease. As an HIV infected person becomes sicker, he progresses from HIV to AIDS, the last stage of the disease. Both HIV data and AIDS data are needed to determine the full spectrum of the HIV/AIDS epidemic. HIV statistical data cited on the previous pages were compiled from several sources. The first includes agencies that require HIV testing for admission into their organization, such as Job Corp and the U.S. military. The other sources of data are 25 of the 32 states which collect HIV as well as AIDS data.

However, we now understand that the CDC does not actually know how many Americans in the general population are HIV infected, or how close its estimates are to actual numbers of infections. The reason for this perplexing situation is that the CDC did not recommend that states document and report cases of HIV until December 1998, despite the fact that an HIV test had been available since 1985. While all states have been required to report AIDS cases to the CDC since the beginning of the epidemic, many states still do not report those infected with HIV, who have not yet progressed to AIDS. **This HIV (non- AIDS) category of infection represents the vast majority of those affected by the disease. Women and African Americans are more likely to be in this stage of HIV progression.**

Though the CDC made its recommendation for states to report HIV cases nearly three years ago, only thirty-two states do so now. That does not include California and Pennsylvania, two of the states with the highest cumulative cases of AIDS. New York, another state with exceptionally high cumulative cases of AIDS, just began collecting HIV data in 2000. Its figures are not yet included in the CDC reports on numbers of HIV infections in America.

It typically takes a decade or more for HIV infection to progress to AIDS. When the CDC only counts the number of AIDS cases, it is gathering information about HIV infections that happened years ago. If we also consider that the CDC is not counting new HIV cases from states with some of the highest AIDS rates, we must conclude that the agency can only guess about the number of people who have recently become HIV infected. **The CDC's estimation of 40,000 new HIV infections each year has not changed for the past ten years.** These facts lead NCBW to believe that, unfortunately, the number of HIV infections in the Black community is underestimated.

Approximately thirteen years ago, the first Presidential Commission on AIDS warned that "continual focus on AIDS rather than the full spectrum of HIV disease will leave our nation unable to deal adequately with the epidemic." The Commission noted that the **"continued emphasis on AIDS has also impeded long-term planning efforts necessary to effectively allocate resources for prevention and health care."**^{vi} Though this observation has proven to be correct, it was forcefully opposed by AIDS advocates. They believed that a fear of breaches of confidentiality, if HIV test results were reported, would deter those at risk from seeking testing. This fear has proven unfounded. For twenty years, all states have reported AIDS cases by name to the CDC. During that time there has been only one breach of confidentiality. Even in that one case, the name of AIDS patients were never released to the public, and the person responsible for the breach was legally prosecuted and punished. There is also no evidence that AIDS reporting deters testing.

Regrettably, at the time of the 1988 Commission's recommendation, the U.S. Public Health Service and policy makers acquiesced to the unyielding pressure from AIDS advocates and did not accept the recommendation. The results have been devastating. While the country's attention was placed on AIDS, the virus silently spread through communities of color and more and more women became unknowingly infected. We are only now learning the extent of the disease's progression made years ago, and the casualties are of immense proportions.

HIV/AIDS CARE AND PREVENTION FUNDING FOR WOMEN

Two identifiers determine the location of the current HIV epidemic. First, the number of new HIV infections that have not yet developed into AIDS in a given geographical location. Second, the number of new HIV infections among a specific demographic group such as gay men or African American women.

One of the critical reasons to document new HIV infections is to insure that money and other resources to prevent further spread of the virus are targeted to those areas where the epidemic currently is. The number of AIDS cases documented in a particular locality has historically determined how much money and services it will receive from federal and state sources. The more AIDS cases there are, the more money the locality will receive. **African American women and children were not among the first to become infected in large numbers, therefore their numbers of AIDS cases are not as high as those who were first infected and have progressed to the end stage of the disease.** We now know that new HIV infections among African American women and young adults are growing at an alarming and disproportionate rate. If their HIV infection has not yet progressed to AIDS, a number of federal and state officials do not count it in determining the amount of funding to be allocated to their geographical locality, or in the level of resources specifically targeted to them. Consequently, many HIV positive people are being denied access to appropriate care, treatment and other resources. African American communities and organizations, in general, have not received a proportionate share of resources to prevent additional HIV infections and to care for those already living with the virus.

A 2000 U.S. General Accounting Office investigation into federal HIV/AIDS spending found that treatment and care for HIV infected women and African Americans are funded at much lower levels than their high HIV infection rates warrant.^{vii} This is a direct result of the unfair resource allocations based upon AIDS cases only, rather than the full scope of the HIV/AIDS disease.

A lack of appropriate resources has had detrimental and frightening outcomes for the vast majority of HIV positive African American women. These women must now add the menacing burden of dealing with their own health to the many other demands of their lives. When women become infected, the ripple affect of harm is often far reaching. The majority of HIV positive African American women are already economically disadvantaged,^{viii} they are generally mothers, and they often do not have the relational stability with the fathers of their children, or any 'significant other' male, who provides them with financial and emotional support so desperately needed.

While the mother is living with HIV, she needs considerable assistance to continue as the primary care taker for her children as long as possible. And, when she is no longer living, the children must still be cared for. We can only guess at the number of children in American who are orphaned as a result of AIDS. Add to it the scores of children who are placed in foster care because there is no relative, including a father, who is capable of, or has the desire to care for them. When women are infected, many people are affected. Women living with HIV/AIDS must receive maximum assistance from public agencies, communities and families, both biological and extended.

Though it appears that presently the vast majority of African American women living with HIV/AIDS are economically disadvantaged, NCBW members are hearing of more and more upper income, professional African American women who are testing HIV positive. Moreover, the high rates of sexual activity and multiple sex partners that already exist on college campuses cause some researchers to believe that, unless the sexual practices of American college students significantly change, the next wave of new HIV infections will be on college campuses.

Many African American female students will come from communities where the virus has already claimed numerous victims. Consequently, they will be at greater risk of going to college already infected (often not knowing of their infection) or encountering an African American male partner who is HIV positive. These students will make up the majority of the future African American middle class. Their dream is to be educationally and socially prepared, at the college of their choice, to become leaders for our people. Unfortunately, they face being confronted with an insidious sexually transmitted disease that can truly be a dream destroyer.

HIV/AIDS RESEARCH AND WOMEN

NCBW also learned that HIV reacts differently in men than in women. AIDS researchers have found that women's bodies seem better able to naturally hold down the AIDS virus. However, this has not worked to the benefit of women because they become sick and die faster than men.^{ix} The findings could mean that women need to be diagnosed and treated earlier than men. This must be more closely investigated. During the early years of the epidemic, even though it was obvious that women were affected, they did not represent a significant portion of those diagnosed with AIDS. Consequently, they were not a focus of research, prevention or care. Today, though women represent a large percentage of people living with HIV disease they are still not proportionally represented in clinical trials and other research efforts that specifically address their unique needs.^x This must change.

HIV/AIDS PREVENTION

HIV/AIDS prevention is an area where each of us can be a major contributor. In our homes, schools, churches, work sites and organizations, we can participate in prevention strategies and become a spokesperson for common sense in the prevention campaign. NCBW has identified several prevention approaches on which we have determined to focus.

PERINATAL HIV/AIDS PREVENTION

As more and more women become infected with HIV, the disease affects more and more children. It is in this crucial area that NCBW, as a committed and concerned group of black women, can have the most lasting and positive impact by working to eliminate prenatal HIV transmission from mother to child.

A significant number of HIV-infected women are still not tested and remain undiagnosed according to the Institute of Medicine^{xi}. As a result, by the end of 1999, nearly 8,000 perinatally acquired AIDS cases^{xii} had been recorded in the U.S. The vast majority (84 %) were Black and Hispanic children. What makes this even more alarming is that nearly all of these perinatal cases could have been prevented. Perhaps the single, most significant achievement in the battle against HIV/AIDS has been the discovery of medical interventions to virtually eliminate perinatal HIV transmission. Science has made it possible that few, if any, babies will ever have to be born with an HIV death sentence. Yet, despite the fact that perinatal transmission can be virtually eliminated -- the CDC estimates that 300-400 babies continue to be born with HIV infection each year in the United States.^{xiii}

- ***Routine HIV Testing of Pregnant Women***

In 1995, the CDC issued recommendations requiring all health care providers to counsel pregnant women about HIV and offer voluntary testing with informed consent. No other prenatal medical screening required such extensive pre-test criteria to be performed. Despite promoting voluntary HIV testing of pregnant women for five years, nearly half of all pregnant women are still not tested according to the CDC's own data.^{xiv} This increases the number of children who will become infected during or after birth. The CDC has conceded, "The birth of every HIV-infected child is a sentinel health event signaling a missed prevention opportunity."^{xv} Clearly, far too many women and infants are slipping through the cracks under the CDC's own recommended approach. Relying on voluntary prenatal HIV testing has obviously not been an effective policy to identify all women and children who need medical intervention and, therefore, has failed to maximize prevention opportunities.

Of the 449 children with perinatally acquired AIDS born in 1995-1997, 35% had mothers who were not tested for HIV before birth.^{xvi} Roughly 15% of HIV infected pregnant women receive no prenatal care. And only 47% of women with HIV receive "adequate" prenatal care, according to researchers.^{xvii} Routine HIV testing of pregnant women provides the opportunity for maximum intervention and care for the HIV infected mother and for her unborn child.

- *Newborn Testing*

Most states require newborns to be tested for a number of diseases and conditions such as Sickle Cell Disease, Hypothyroid disease and some metabolic disorders. None of these is as prevalent or as deadly as the HIV virus. Yet, only two states – New York and Connecticut – require newborns to be screened for HIV. Routine testing of pregnant women and mandatory testing of newborns should both be utilized. Prenatal screening provides for early intervention and newborn testing ensures that all babies are identified and every mother and child affected by HIV is guaranteed a safety net.

New York has required HIV testing of all newborns since February 1997. "Universal newborn HIV testing has resulted in the identification of all HIV-exposed births in the state" according to Dr. Guthrie S. Birkhead, Director of New York Health Department's AIDS Institute. "...newborn testing has allowed hospital and health department staff to ensure that over 98 percent of HIV positive mothers are aware of their HIV status and have their newborn referred for early diagnosis and care of HIV infection. Furthermore, of the 4,022 HIV-exposed infants identified under the laws since 1997, 99.4% have had follow-up medical care."^{xviii}

Opponents of newborn HIV testing insist that it will deter women from seeking prenatal care and thereby, drive the epidemic underground. "Rates of participation in prenatal care in New York State...have been increasing gradually over recent years," according to Dr. Birkhead, there has been "no detectable change" in prenatal participation trends "that might be related to the newborn testing program."^{xix} Assemblywoman Nettie Mayersohn, author of the state's Baby AIDS law notes that, "Women are getting tested in higher numbers, more women are receiving prenatal care, and lives are being saved."^{xx}

In October 1999, Connecticut enacted a Baby AIDS law requiring HIV testing of every newborn whose mother's HIV status is unknown. According to two studies presented at the annual meeting of the American College of Obstetricians and Gynecologists, implementation of the law has been successful in increasing the number of pregnant women who are tested. Dr. Uranian Magriples of Yale University conducted the first study. Before the law was enacted, 38.9% of the 187 women who obtained prenatal care at a Yale health care clinic were tested for HIV. After the law was enacted, 91% of women were tested. Dr. Magriples said that she initially opposed the law because she thought it was coercive. Now she says the law "appeals to the maternal instinct in these women to protect their babies."^{xxi}

Dr. William Cusick of Stamford Hospital in Connecticut conducted the second study. The study followed 2,239 pregnant women, seven of whom were identified as HIV-positive, and two additional cases – a husband and a child – were identified after a positive test result in the pregnant woman. Dr. Cusick said, "Without the mandatory testing, I think we would have missed six of these nine cases."^{xxii}

In addition to preventing babies from becoming infected with HIV during delivery, newborn screening offers many other benefits. Those babies with infected mothers, who are fortunate enough to escape HIV before and during delivery, are still at risk for HIV if the mother breastfeeds. It is beyond tragic for a baby to escape infection only to become unknowingly infected by a loving, yet unsuspecting, mother, via breastfeeding. Yet, it continues to occur.

Newborn testing also offers additional hope to those babies who are infected. With early knowledge of a child's HIV status, appropriate medical care can protect and enhance the child's health, thereby, prolonging and improving life.

Studies have also concluded that newborn HIV testing saves money. "Annual routine newborn HIV testing would encompass 3.8 million infants, identify 1,061 infected mothers, avoid 266 newborn infections, and would cost \$7,000 per life-year gained" in the United States according to a study published in the *Journal of Acquired Immune Deficiency Syndromes*.^{xxiii} The average total lifetime charges for care of a child with HIV infection is estimated at \$491,936.³⁶ The researchers concluded that routine testing of newborns is, therefore, "cost effective."^{xxiv}

Opponents also maintain that testing is unreliable and may result in the treatment of uninfected children with highly toxic medications. Rapid HIV tests can now produce 100% accurate results in as little as 30 seconds. The sensitivity and specificity of these rapid assays are comparable to other HIV diagnostics. A negative rapid test does not require further testing, and negative results indicate the absence of HIV infection. There is an extremely slim possibility that some tests may produce a "false positive" for HIV. Therefore, a reactive rapid test must be confirmed by a supplemental test. Results from a confirming test may be available within 12 hours of the infants' birth.^{xxv} Studies have yet to show that ZVD has caused any significant adverse health consequence to children. Regardless, a short course of ZVD over several hours is far less dangerous than risking the alternative.

What seems to be the crux of the debate about testing a newborn for HIV, is that the procedure also reveals the HIV status of the mother. This, critics say, violates the mother's privacy, or her "right not to know her HIV status." It appears that privacy, to some, should take precedence over all else, including saving the lives of women and babies. This view is based on ideology about guarding the privacy of someone's sexual lifestyle, and fears of harassment that found their beginnings in the early days of the epidemic and still prevail to some extent today, twenty years later. There is no scientific data to indicate that loss of privacy has been an outcome of newborn testing policies. Anecdotally, few, if any, mothers have voiced an opinion that protecting the health of their baby jeopardizes their own personal rights.

Newborn testing is supported by a large portion of the medical community, the elected branches of the Federal government and, overwhelming, by the public. The American Medical Association, the nation's largest and most respected doctor's organization, endorsed mandatory HIV testing of all pregnant women and newborns for HIV in 1996.

NCBW was heartened when Congress passed without dissent and President Clinton signed into law the 2000 Ryan White CARE Act Amendment. It contained a provision encouraging all states to enact newborn testing policies. States that pass such laws would be eligible for up to \$4 million in federal funds to support state efforts to reduce perinatal HIV transmission. We agreed with former Congressman Tom A. Coburn, M.D., the bill's author and a practicing physician who has delivered AIDS babies, when he stated, "This amounts to a federal endorsement of universal HIV newborn testing as a routine practice."^{xxvi} At the time of completion of this document, Congress had not yet appropriated any of the much needed funding.

NCBW also shared the bewilderment of a Wall Street Journal writer, "To save the babies we need to know their HIV status at birth, and that of their mothers during pregnancy.... How did the American system arrive at a point where it discovers it can save HIV-infected babies and then decides not to?"^{xxvii} One must wonder why, with the obvious significant benefits and widespread support for newborn testing, such a program has not been recommended by the CDC or implemented nationally.

Over the past decade, newborn testing legislation has been introduced nationally and in numerous states. But, in nearly every case, the legislation has been successfully derailed or fundamentally altered. With New York clearly demonstrating that mandatory testing of newborns saves lives without endangering women and their babies, NBCW strongly supports this medically sound approach.

- ***Pregnant Women in Prison***

It is important to note that the newborns we are talking about include those born to women in prison. Prison inmates are five times more likely to have AIDS and ten times more likely to have HIV.^{xxviii} In most states, female inmates had higher HIV infection rates than male inmates, according to a 1999 Justice Department report. For female prisoners, the Federal Bureau of Prisons requires such testing at the time of admission and upon release. Incarcerated pregnant women must be routinely tested and guaranteed appropriate medical care if infected.

- **Partner Notification**

Partner notification has been an extremely effective tool for disease control but has been minimized in our battle against HIV. Notification programs are particularly beneficial to protect women from HIV. This is because many women do not engage in high-risk behaviors but have a partner who does. Without guaranteeing these unsuspecting victims a right to know that they are at risk, how else can they protect themselves?

NCBW members know, or know of, women who believed they were in a mutually monogamous relationship only to discover their partner had infected them. For example, a New Yorker became aware of her own infection by her husband only after their child was diagnosed with AIDS during an autopsy.^{xxix} A woman who works at an inner city clinic in New York was forced to remain silent while one of her HIV-positive clients attempted to have a baby with his wife who was unaware of his status.^{xxx} Many women have been allowed to become infected by people they trusted. They did not know they were at risk and no one warned them. In some cases, the law forbade them from being notified, even when medical and public health officials had that information.

It seems that over the twenty years of the HIV/AIDS epidemic, Congress, the CDC and others responsible for protecting the public's health have not been aggressive about putting into place guarantees that protect people's right to know if they have been exposed to HIV. In fact, the Texas Supreme Court ruled in 1998 that there is "no statutory or common-law duty to notify" a woman "that she was at risk of contracting the HIV virus."^{xxxi} The consequences of this negligence have been devastating.

Partner notification essentially requires two steps. The first is to counsel all infected individuals about the importance of notifying their partner or partners that they may have been exposed. The second is for their doctor to forward the names of any partners identified by the infected person to the Department of Health. Then, specially trained public health professionals confidentially complete the notification. In all cases, withholding his or her name from the partner being notified protects the privacy of the infected person. Because names are never revealed, the infected retain their anonymity.

Partner notification has proven to be highly effective with other contagious and sexually transmitted diseases. There is no evidence that partner notification programs discourage individuals from being tested. Between 50% and 90% of those who tested HIV positive cooperate voluntarily with notification.^{xxxii} Further, even higher proportions of those partners contacted – usually 90% or more – voluntarily obtain an HIV test. But only 10% or less of people who have recently tested HIV-positive manage, by themselves, to notify their partners.^{xxxiii}

Four out of every 10 HIV-infected people at two New England hospitals failed to inform sex partners about their condition, and nearly two-thirds of those didn't always use a condom researchers from Brown University found. The researchers conclude that “many HIV-infected individuals do not disclose their status to sexual partners” and those who do not disclose are less likely to wear condoms.^{xxxiv}

There is no federal policy requiring each state to notify people that they have been exposed to HIV disease. Consequently many states have ineffective, at best, partner notification programs. NCBW believes that in oftentimes, partner notification is a simple matter of life and death. Remaining silent while others are at risk is equivalent to acting as an accomplice in delivering a death sentence. Unfortunately, it appears that this deadly silence pervades the existing prevention paradigm and is, in large part, responsible for the failure to end this epidemic. It has cut short the lives of hundred of thousands of Americans who were unknowingly infected.

• Sexual Behavior and HIV Prevention

It seems that most prevention messages have been focused on “safer sex”, the use of a condom correctly each time of intercourse, as a way of avoiding HIV infection. These messages may have unintentionally placed individuals at risk, by given them a false sense of security about protection from disease transmission while using a condom. No one disputes that condoms can reduce the chance of HIV infection, but a “vigorous condom-promotion policy could increase rather than decrease unprotected sexual exposure if it has the unintended effect of encouraging greater sexual activity,” according to a recent study printed in the prestigious British medical journal, *The Lancet*. Researchers from the University College London conclude that while “the benefits of condom use to individuals exposed to HIV or STDs are substantial [and] well documented, ...it is hard to show that condom promotion has had any effect on HIV epidemics.” They found that “increased condom use will increase the number of transmissions that will result from condom failure” and could affect decisions of individuals to switch from inherently safer strategies of abstinence or fewer and more selective partners to the riskier strategy of developing or maintaining higher rates of partner change plus reliance on condoms.^{xxxv}

A benchmark report released during the summer of 2001 by the U.S. Department of Health and Human Services indicates that correct and consistent use of condoms reduced the risk of HIV infection by 85%. This is not prevention, but risk reduction, because there is still a significant risk for infection. Furthermore, the report also points out that condoms were ineffective against the three most prevalent STDs, chlamydia, genital herpes and human papillomavirus (HPV). HPV is the cause of nearly all cases of cervical cancer and is also linked to oral, anal, and prostate cancer.^{xxxvi}

NCBW supports providing accurate and complete information about condoms to adolescents in a manner that does not sanction or encourage their involvement in sexual activity. Some sex educators, policy makers and others believe that if condoms do not appear nearly perfect in preventing all sexually transmitted diseases, people, especially teens, may be discouraged from using them at all. This argument may seem understandable. However, the first line of defense in our battle against AIDS and other STDs is to tell the truth... to give accurate and honest information.

NCBW's greatest support is for helping adolescents to abstain from sexual activity as unmarried teens. As the many reports about HIV indicate, it is indeed a behaviorally driven epidemic and is virtually preventable. Sexual abstinence for our youth, limiting numbers of sexual partners for sexually active adults and mutual fidelity within marriage are behaviors that can bring this epidemic to a stand still. However, the African American community in general has not made these the clarion call of its HIV/AIDS prevention messages.

There seems to be a widespread belief among many experts that promoting an abstinence campaign to young African Americans, or expecting the majority of African American adults to develop committed, lifelong relationships with one partner is an exercise in futility. It may surprise some people, that from 1890 to 1960, around eighty percent of all African American homes were headed by a husband and wife.^{xxxvii} Currently, research documents that Black youth are less likely to use tobacco, alcohol and drugs than white youth.^{xxxviii} If Black adults have a history of strong, enduring marriages, and Black youth can exhibit self-control in certain areas of their lives, it is perfectly reasonable to believe that adolescent sexual abstinence and marital fidelity are obtainable, even in today's culture. Furthermore, recent data indicate that for the first time in decades, there has been a significant decline in sexual activity among teens, including Black teens, between the ages of 14-19.^{xxxix}

A prevention campaign targeted to African Americans of varying ages and socio-economic backgrounds must be developed and aggressively spread throughout our communities. Its message must promote sexual responsibility, which includes self-restraint and respect for self and others. It must articulate a positive message about the great value of sex and the immense benefits of sharing it with one life-long partner. We must train our youth to develop trusting, mutually respectfully relationships that are not base on sex. And, for those young people who will undoubtedly be sexually active regardless of the message, we must provide them with accurate risk reduction information. More importantly, we must show them unconditional love as we continue to do all we can to help them make and follow through on the choice to again postpone sexual activity. This first must include modeling healthy and responsible behaviors for our youth.

A more important charge of the campaign would be to rekindle the racial pride that makes us want to protect one another and ourselves. The kind of pride that ignited and sustained personal sacrifices

made by African Americans in generations pass to insure the strong survival of the race. At this time in our history, we find ourselves at a precipice. We can continue to embrace behaviors and attitudes that have proven to cause great harm to our people as a whole. We can stand by and watch our numbers and life opportunities be decimated by HIV/AIDS and the myriad of challenges we face daily in our communities. Or, we can rally together, determine to change, determine what changes are needed, how to make the changes, and then change. Though others can and should help, the first, and greatest responsibility is ours.

One of the changes that we know will make a difference for our people, even in our fight against AIDS, is rebuilding and strengthening our families. We must be unapologetic about the need to bring more of our men back into the homes as loving and supportive husbands and fathers and to break the cycle of single parenting in our communities. The data is replete with information that documents much higher risks of early sexual involvement and multiple sexual partners (both risks for exposure to HIV disease) for youth raised in single parent households than those raised with the father and mother in the home. But, there is another danger. Our women are left very vulnerable in ways we may not have considered.

In 1985, Dr. Robert Redfield, Jr., M.D., based on his extensive treatment of AIDS patients and AIDS research at the Walter Reed Army Institute of Research, suggested that the breakdown in the American family is one of the major causes for the rise in new HIV infections. He understood that the greatest risk factor for contracting any sexually transmitted disease is having multiple sexual partners. He observed that adults living in communities where most of the homes are headed by single parents have opportunities to have more than one sexual partner over a given period of time. Certainly much more so than if they were married. Dr. Redfield then predicted that, because single parenting was particularly high among African Americans, by the early 1990s, the number of their deaths from AIDS would be greater than the number of those as a result of homicides. Though Dr. Redfield was considered an alarmist at the time, regrettably, we now know he was correct. AIDS is the number one cause of death in African American men between the ages of 25 and 44 years of age, and the number two cause of death for African American women in the same age group.³¹

Our men can be an even more vital part of thriving, loving families as we begin to focus on the importance of mutually respectful relationships that have the potential to develop into life-long, committed marriages. NCBW will provide support for the many responsible single and married parents who are struggling to raise their children to become healthy, productive adults.

CONCLUSION

Each day a disturbing number of African American women are newly infected with HIV disease. NCBW believes it will require an arsenal of weapons on every front to stop this tragedy. We call for immediate and swift action, first, from all facets of the African American community. We, as a people, must protect ourselves from possible irreparable harm resulting from behaviors and attitudes that keep this preventable disease alive. We must also rally to protect and care for those already living with the disease, whether infected or affected by it. In reality, that includes every member of our community.

We demand that the federal, state and local public health services perform the duties for which they were established. They must efficiently and speedily implement tried and proven public health strategies which have controlled and eradicated communicable and infectious diseases throughout the centuries. Lastly, NCBW calls upon our leaders, elected, appointed and self-proclaimed, to vigorously support what we know is right and in the best interest of all Americans.

Let us not look back, even one more day from now, bemoaning the fact that we are continuing to make unwise choices and are floundering in our inaction. The future of our children and of our ability to be a healthy, productive and influential people, greatly depend on whether or not we can overpower and annihilate HIV/AIDS. During the history of our journey in American, African Americans have faced and triumphed over almost insurmountable obstacles. We can also defeat the HIV/AIDS enemy by employing the same values, tenacity and will that helped us throughout years pass.

NCBW declares that twenty years from now we will celebrate victory over another abominable force that greatly tested our strength as a people. We will know that we bonded together to defeat the foe and won!

NATIONAL CONGRESS OF BLACK WOMEN**RECOMMENDATIONS****FOR THE****ERADICATION OF HIV/AIDS AMONG AFRICAN AMERICAN WOMEN**

Based on information revealed during NCBW's review of HIV/AIDS disease and its impact on African American women and children, we make the following recommendations for governmental policies, and community and individual action. These recommendations are not all inclusive. They reflect what we consider to be the essential steps in slowing and ultimately ending the HIV/AIDS epidemic among African American women. More comprehensive strategies will be forthcoming as the NCBW HIV/AIDS Initiative evolves.

Federal, State and Local Governments

1. Congress should require all states to document and report to the federal Centers for Disease Control and Prevention (CDC) HIV as well as AIDS cases.
2. Policies, funding and other resources should be determined and allocated based on documented and reported HIV and AIDS cases instead of AIDS cases alone.
3. All states should be required to have effective partner notification programs.
4. All states should be required to provide routine testing of all pregnant women.
5. All states should be required to provide mandatory HIV testing of all newborns.
6. Congress should appropriate the funds needed to support state efforts to reduce all perinatal HIV transmission.
7. Congress should conduct hearings on women and HIV/AIDS.
8. Women should be proportionally represented in clinical trials and other appropriate HIV/AIDS research efforts.
9. Female specific HIV/AIDS drugs and treatments be expeditiously developed, tested and made available to women.

10. Equitable funding should be allocated to African American run community-based organizations for HIV prevention and care to African American women.
11. Increased funds should be allocated to the Office on Women's Health, U.S. Department of Health and Human Services to enhance its ability to track and effectively address the impact of HIV/AIDS on women.
12. African American women representing communities with high HIV infection rates should be equitably represented on boards, community planning committees and all other governmental decision making councils in respect to HIV/AIDS.
13. Funds should be allocated to African American community-based organizations to provide education in the promotion of sexual abstinence for youth, limiting numbers of sexual partners for sexually active adults and mutual fidelity within marriage.

Community

1. Create a non-threatening environment in which HIV/AIDS issues can be openly.
2. Develop and facilitate HIV/AIDS programming and training
3. Network with other community based organizations to maximize effort.
4. Provide and expand resources for care of those living with HIV/AIDS disease.
5. Endorse and model positive social attitudes and behaviors.

Individuals

1. Learn as much as you can about HIV/AIDS
2. If you are an adolescent, postpone sexual activity at least until you are out of high school
3. If you are unmarried, and are sexually active, limit the number of your sexual partners; know your HIV status and that of your partner; and use a condom consistently and correctly each time.
4. If you are married, practice fidelity within your marriage.
5. Endorse and model positive social attitudes and behaviors.

NATIONAL CONGRESS OF BLACK WOMEN

HIV/AIDS INITIATIVE

PLAN OF ACTION

TO PROVIDE ASSISTANCE IN THE FIGHT AGAINST HIV/AIDS

The National Congress of Black Women (NCBW) believes that the strategies to combat the HIV/AIDS epidemic among African American women and children must be multi-faceted. The organization will focus its efforts on education, family, economics and the entertainment music culture by implementing specific activities.

ACTIVITIES

1. Establish a NCBW HIV/AIDS task force.
2. Serve as national advocates for HIV/AIDS eradication.
3. Include the issue of HIV/AIDS in other NCBW initiatives such as economic empowerment for women.
4. Publish and/or distribute information about HIV/AIDS in the African American community.
5. Develop training materials of NCBW members
6. Provide HIV/AIDS prevention and care training to NCBW members.
7. Develop Speakers Bureau of NCBW members who successfully complete training and can provide national, state and local training and other presentations.
8. Network with other local, state and national non-profit organizations with HIV/AIDS initiatives to maximize NCBW's efforts.

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